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ABSTRACT

This issue of "OSERS" addresses the subject of independent living of individuals with disabilities. The issue includes a message from Judith E. Heumann, the Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), and 10 papers. Papers have the following titles and authors: "Changes in the Rehabilitation Act of 1973 and Federal Regulations" (John Nelson); "Title VII: A Major Step Forward" (Robert E. Michaels); "Perspectives on Personal Assistance Services" (Bob Kafka); "Consumer-Driven Supported Employment: Consolidating Services for People with Significant Disabilities" (John D. Westbrook); "The Effects of Insurance Benefits Coverage: Does It Affect Persons with Spinal Cord Injury?" (Denise Tate and Julie Daugherty); "Learning from the Experts: Best Practices in Rural Independent Living" (R. Mark Mathews); "Improving Management Effectiveness in Independent Living Centers through Research and Training" (Quentin Smith and others); "Independent Living: Driven by Principles of Democracy" (Duane French); "How Parent Networks Are Working with Independent Living Centers" (Martha Ziegler); and "Independent Living and Personal Assistance Services: The Research, Training, and Technical Assistance Programs at the World Institute on Disability" (Jae Kennedy and others). (References accompany most papers.) (JDD)

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Independent Living

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A MESSAGE FROM THE ASSISTANT SECRETARY

The Independent Living Movement

Judith E. Heumann

Assistant Secretary for Special Education and Rehabilitative Services

The 1992 Amendments to the Rehabilitation Act present a radically different view of disabled people. The rehabilitation program has evolved from a program that served only those disabled people presumed to be capable of engaging in gainful employment to a program that presumes that people with significant disabilities have a right to employment services.

The new provisions of the Rehabilitation Act Amendments clearly delineate independent living centers as empowering, advocacy-oriented organizations. I like to refer to the section of the law which talks about:

"... independent living, consumer control, peer support, self-help, self-determination, equal access, individual and system advocacy, leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society."

Independent living is really at the very heart of all we strive for. It is the goal of special education, rehabilitation, research, health-care reform, and policy development to live independently in the community, participating fully in as many aspects of life as possible.

Many people in our society are simply not used to thinking of significantly disabled people as members of the competitive workforce or the community in general. It is up to us to set the pace, establish the vision, and create an environment to bring about change. And of course, this is what the independent living movement is all about — bringing about change.

I think this movement, more than any other, gives us both the model and the method for change. It shows us, by its very successes, how dedication can overcome discrimination, involvement can overcome intolerance, and activity can overcome apathy.

In addition to the Rehabilitation Act, we have the help of laws such as the Individuals with Disabilities Education Act (IDEA) mandating appropriate education for disabled children. We have the Americans with Disabilities Act (ADA) prohibiting discrimination against disabled people in employment, public accommodations, and in state and local government. These extremely important pieces of legislation are producing changes.

We now have more than 200 independent living centers (ILCs) across the United States. I really see these centers as change agents. Not only change agents for disabled people, but change agents for the community as a whole, change agents for integration, change agents for society. This is a large challenge and a large responsibility, but it's certainly a worthy one.

Change takes time. But we as disabled people appropriately feel that we have no time. Every day that goes by denying millions of disabled people our rights is not tolerable. Yet the reality of the independent living movement is that we have to be in this struggle for the long run. Independent living centers in the United States are not large, well financed organizations. But they have a large mandate — change their community, their state, their country and to work with the international movement to improve the world.

At the same time, the independent living movement is analyzing its weaknesses and working on expanding its base. The centers are expanding to be more representative of the community across disabilities, to be representative of older people, people with AIDS, people with psychiatric problems, cognitive and learning difficulties, to focus on women's issues, issues of African Americans, Latin Americans, Native Americans, Asian Americans, and people having alternative life styles. This expanded movement has helped the independent living movement become aligned with the other civil rights movements.

In OSERS, we intend to continue to look at the various approaches to independent living and ILCs such as working in cross-disability coalitions, working with minority issues, working with state and local governments on issues such as health reform and systems change. Now that the law stipulates that ILCs are to be managed by disabled people and serve more people with significant disabilities, ILCs will be on the cutting edge of developing new and effective modes of service delivery.

I believe a strong independent living movement that echos the words of President Clinton in emphasizing independence, not dependence, inclusion, not exclusion, empowerment, not paternalism, will ensure that the quality of life for disabled people will improve. Our reality is that together we have begun to create a better world where we as disabled people are beginning to be respected for who we are and who we can be.

Independent Living

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Changes in the Rehabilitation Act of 1973 and Federal Regulations

John Nelson
Chief

Independent Living Branch
Rehabilitation Services
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Office of Special Education and
Rehabilitative Services

Background

Title VII of the Rehabilitation Act of 1973, as amended was extensively changed by the Rehabilitation Act Amendments of 1992 (1992 Amendments), effective October 29, 1992 and the technical amendments to the Act (1993 Amendments), effective August 8, 1993. This article will discuss the prior and projected activities of the Department of Education concerning those portions of the 1992 and 1993 Amendments and subsequent draft regulations that affect the independent living programs contained in Title VII of the Act. All references to regulations are references to the proposed regulations in 34 Code of Federal Regulations, parts 364, 365, 366, and/or 367. Readers are encouraged to review both the Act and regulations.

The Department formed a policy group to prepare proposed and final regulations for Title VII. This group consisted of representatives from the Rehabilitation Services Administration (RSA), the Office of the Assistant Secretary in the Office of Special Education and Rehabilitative Services (OSERS), and the Department's Office of General Counsel, Office of Management and Budget, and Office of Evaluation.

The policy group approached its tasks with three basic assumptions:

(1) The laws cannot be changed by the regulations.

(2) The regulations should "stand on their own" and not require a copy of the statute to enable an individual to use the regulations.

(3) The regulations should be primarily skeleton regulations based on the statute, expanding on the statute only where clarification is necessary or where program experience or legislative history indicate.

The work of the policy group continued for more than a year. Because of the statutory timeline and the extensive history involved with the development of indicators for Centers for Independent Living (CILs), that portion of the proposed regulations referring to standards and indicators was given priority. The notice of proposed rule making (NPRM) on the standards and indicators was published for comment on October 27, 1993. The comment period, originally scheduled to end December 13, 1993, was extended to February 22, 1994.

There were three meetings and three teleconferences scheduled to facilitate dialogue on the draft proposed regulations. During the meetings and teleconferences, the policy group and others from the Department were present to receive comments and suggestions, discuss why certain decisions were made, and discuss other issues related to the development of the regulations. The comments and suggestions were carefully considered prior to the publication of the proposed regulations in the *Federal Register*.

Future Activities

A 60-day comment period is planned following publication of the proposed regulations. During this period, all parties will have an opportunity to review and provide written comments on the proposed regulations. The comments are open for public review in RSA and will be carefully considered in developing the final regulations. The decision about how substantive comments are addressed will be reflected in the preamble to the final regulations when they are published in the *Federal Register*. Policy group activities resulting from the NPRM will include: comment analysis, policy decisions, response preparation, and regulation rewriting to reflect the Department's decisions in response to the comments. The final *Federal Register* publication of the regulations will include regulations for all of Title VII, including the standards and indicators.

Concurrent with the publication of the NPRM of the remaining Title VII regulations in the *Federal Register*, the proposed Title VII data collection and reporting forms will be sent to the Office of Management and Budget (OMB) for review and publication for comment in the *Federal Register*. These forms must have OMB clearance prior to publication of the final regulations on the Title VII programs.

The 1992 and 1993 Amendments restructure Title VII of the Act by creating two Chapters. Chapter 1 contains three parts — A, B, and C. Chapter 2 does not contain separate parts.

Chapter 1

The purpose of Chapter 1 is to promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities. Chapter 1 seeks to promote the integration and full inclusion of individuals with disabilities into the mainstream of American society by:

(1) providing financial assistance to states for providing, expanding, and improving the provision of independent living services;

(2) providing financial assistance to develop and support statewide networks of centers for independent living;

(3) providing financial assistance to states for improving working relationships among state independent living rehabilitation service programs, centers for independent living, statewide independent living councils established under Section 705, state vocational rehabilitation programs receiving assistance under Title I, state programs of supported employment services receiving assistance under Part C of Title VI, client assistance programs receiving assistance under Section 112, programs funded under other titles of this Act, programs funded under other federal programs, and programs funded through non-federal sources.

Part A contains general provisions for all of Chapter 1 and some portions of Chapter 2. The provisions include definitions for centers for independent living, consumer control, program eligibility, state plan requirements, statewide independent living council (SILC) composition and responsibilities, and the specific responsibilities of the Commissioner of the Rehabilitation Services Administration. The definitions contain significant emphases on consumer controlled, cross-disability services from private non-residential, non-profit CILs.

The State Plan for Independent Living (SPIL) is jointly developed and signed by the directors of the designated state units (DSUs) and the chairperson of the consumer controlled SILC. There must be an approved SPIL before Chapter 1 funds can go to a state. The SPIL is a major document that:

- establishes the SILC and describes the extent and scope of the independent living activities of the DSU and CILs in the state;
- describes roles and objectives of the DSU and CILs;

• describes a design for a network of CILs in the state;

• describes how the DSU will make awards and oversee the Part C program in states where the state contributes at least as much as the federal government for the general operations of CILs;

• describes steps to maximize interagency cooperation;

• describes steps to provide outreach to unserved and underserved populations; and

• establishes a method for periodic evaluation of the plan in meeting its objectives.

Part B describes the funds allotment procedure and the authorized use of these funds. The funds may be used to:

• support the SILC;

• provide independent living services to individuals with severe disabilities;

• demonstrate ways to expand and improve independent living services;

• support the operation of CILs;

• support activities to increase the capacities of public or nonprofit agencies and organizations and other entities to develop comprehensive approaches or systems for providing independent living services;

• conduct studies and analyses, gather information, develop model policies and procedures, and present information, approaches, strategies, findings, conclusions, and recommendations to federal, state, and local policy makers to enhance independent living services for individuals with disabilities;

• train individuals with disabilities and people providing services to individuals with disabilities about the independent living philosophy; and

• provide outreach to populations that are unserved or underserved by programs under Title VII, including minority groups and urban and rural populations.

Part C establishes an entity to provide training and technical assistance to CILs and SILCs and describes program funding allocation formulas, transition year procedures, procedures for grants administration of the CIL program for both the federal and state government administrations, procedures for the state operation of CILs, standards and assurances for CILs, and the definition of eligibility for Part C funds.

Chapter 2

Chapter 2 contains the definition for older individuals who are blind; financial allocation of funds, including competitive and formula grant requirements; authorized uses of funds; non-federal matching requirements; eligibility to receive and subgrant the funds; assurances; and data reporting requirements.

This program supports grants to state agencies serving individuals who are blind or visually impaired. These grants support such activities to assist individuals who are at least 55 years of age as:

• providing independent living services to older individuals who are blind;

• conducting activities that will improve or expand services for such individuals; and

• conducting activities to help improve public understanding of the problems of such individuals.

There is a definition of independent living services for Chapter 2. Independent living services include:

• services to help correct blindness, such as:

— outreach services;

— visual screening;

— surgical or therapeutic treatment to prevent, correct, or modify disabling eye conditions; and

— hospitalization related to such services.

• the provision of eyeglasses and other visual aids;

• the provision of services and equipment to assist an older individual who is blind to become more mobile and more self-sufficient;

• mobility training, braille instruction, and other services and equipment to help an older individual who is blind adjust to blindness;

• guide services, reader services, and transportation;

• any other appropriate service designed to assist an older individual who is blind in coping with daily living activities, including supportive services and rehabilitation services;

• independent living skills training, information and referral services, peer counseling, and individual advocacy training; and

• other independent living services, as defined for the rest of the Act.

The Proposed Regulations for Title VII

The organization of the regulations tracks the organization of the Act. Part 364 of the proposed regulations equates to Title VII, Chapter 1, Part A of the Act; Part 365 of the proposed regulations equates to Title VII, Chapter 1, Part B of the Act, Part 366 of the proposed regulations equates to Title VII, Chapter 1, Part C of the Act; and Part 367 of the proposed regulations equates to Title VII, Chapter 2 of the Act.

The proposed regulations incorporate the provisions of the Act. The Department also made certain clarifications and additions where it was deemed necessary.

Part 364

This Part contains the general provisions applicable to all of Title VII, Chapter 1 and also contains several necessary references to Chapter 2. In addition to the definitions in the Act, certain other definitions are proposed. These include definitions for "administrative support services," "advocacy," "attendant care," "cross-disability," "individual with a significant disability," "minority group," "nonresidential," "peer relationships," "peer role models," "significant disability," "transportation," and "unserved and underserved." Clarifying language is added to describe the SILC and SPIL. The DSU's roles for the Part B and C programs are clarified, staffing and development requirements for DSUs and CILs are explained, a further definition of the requirement for networks of CILs is provided, and eligibility for services and who determines eligibility is described. There is also a provision for delegation of authority given to the DSUs. Other post-award conditions are proposed relating to referrals and applications, initiation and development of a SPIL, consumer service records, the prohibition of service durational limitations, standards for providers, personal information, and for the use of expenditures made with non-federal funds in a particular fiscal year.

Part 365

This Part contains specific provisions applicable to the Part B, Chapter 1, Title VII, State Independent Living Services program. The regulations contain provisions describing non-federal matching and prohibition of reversion to donor requirements and conditions for awarding sub-grants and contracts. Finally, provisions are added that require written standards in situations where the provision of IL services furnished by sub-grantees and contractors, other than CILs, do not meet the standards and assurances described in Section 725 of the Act.

Part 366

This Part contains specific provisions applicable to the Part C, Chapter 1, Title VII, CIL program. The proposed regulations provide a definition of a *new* CIL. The regulations expand on descriptions of the appropriate entity to provide training, technical assistance, and selection criteria for competitively selecting the entity. Other proposed regulations focus on appeal procedures for adverse actions against CILs and selection criteria to fund new CILs under competitions directly administered by the Department. The regulations provide a methodology for determining whether states or DSUs are eligible for awarding grants under the CIL program and describe procedures for determining whether a DSU qualifies, or continues to qualify, to administer the CIL program based on the amount of state funds contributed to the program. Clarifying regulations distinguish the difference between procurement and assistance contracts and emphasizes the prohibition of the use of procurement contracts. Finally, state DSUs are provided with the option of increasing the funding level of existing CILs if funds are not sufficient to support a new CIL.

Part 367

This Part contains specific provisions applicable to Chapter 2, of Title VII, the Independent Living Services for Older Individuals Who Are Blind program. Selection criteria are given for making competitive awards when the funding level for this program is less that $13 million. The proposed regulations give the Secretary the ability to consider geographic distribution when making competitive awards and permit state vocational rehabilitation agencies to run the program directly or through sub-grants or contracts.

For additional information, contact John Nelson at 202/205–9362 or write to him at the Rehabilitation Services Administration, Room 3326 Switzer Building, 330 C Street, S.W., Washington, D.C. 20202.

TITLE VII: A Major Step Forward

Robert E. Michaels

President
Resources for Living Independently
Philadelphia, Pennsylvania

Chair
Rehabilitation Act Subcommittee
National Council on Independent Living

In 1992 President Bush signed into law the Rehabilitation Act Amendments. At that time, many congressional staffers and disability advocates called these amendments the most sweeping changes ever — or, at least the most significant modifications since the addition of Section 504 in 1973.

As chair of the National Council on Independent Living (NCIL) Subcommittee on the Rehabilitation Act, I am often asked whether I believe the changes really will have much impact on the rehabilitation system as we know it. The truth is, it is just too early to tell.

It would be very easy to claim that the changes, especially in Title VII, are so far-reaching that the reauthorization must have been an overwhelming victory for consumers. After all, the additional emphasis on empowerment, self-determination, productivity, and integration suggests that we are transforming into action those principles for which we fought so hard in the ADA.

Independent living (IL) philosophy has been formally endorsed with the inclusion of principles of consumer control and direction, cross-disability service provision and representation, and equal access for people with the most significant disabilities.

We can also take pride in the structural changes in the statewide independent living councils (SILCs), liberating funding procedures for Centers for Independent Living (CILs), and strict standards for CILs. These may, indeed, be major victories for disciples of IL philosophy.

On the other hand, these changes may amount to little more than window dressing as rehabilitation professionals, and especially those within the state and federal bureaucracies, move to preserve the status quo. Already, there are indications that this may be happening as we hear about "finely crafted language" being inserted into regulations to obstruct meaningful change. Others have interpreted the law, in the absence of regulations, in a manner which is inconsistent with the spirit of reform that was evident during reauthorization. Still others have taken a resistant "when-hell-freezes-over" approach.

If the traditionalists are, in fact, serious about resisting changes in the Act (and NCIL believes they are), then disability advocates must remain ever vigilant. And the areas of greatest resistance will coincide with those that we see as our major victories. In Title I, these are likely to be eligibility determination, consumer control in the IWRP process, and the appeal systems. Title VII, which is where NCIL concentrated most of its energy during reauthorization, contains most of the rest.

Making the State IL Councils Work

Several meaningful reforms affect the structure, composition, and authority of the SILCs. Prior to this reauthorization, appointments to the councils were made by the director of the state vocational rehabilitation agency. The Council, usually following the direction of state agency staff, prepared a five-year IL plan (as opposed to the three-year state IL plan submitted to the Rehabilitation Services Administration (RSA) in order to receive funding) which was given to the state director for his or her consideration.

Today, the SILCs will be truly consumer controlled with at least 51 per-

An advocate's analysis of changes in Title VII's Independent Living Program

cent of its members being people with disabilities.

Appointments to the councils are made by the governor or, when one exists within a state, an appointing authority. The SILCs will supervise and evaluate the staff and will develop and sign, in conjunction with the state agency, the state IL plan. The states and the Rehabilitation Services Administration must follow the plan when distributing funds authorized by the Act. Because of the amendments, the SILCs finally have *real* authority to carry out their responsibilities.

Still, problems need to be worked out — for instance, where the councils should be located. A technical amendment has been written confirming that the councils are not established within a state agency and, therefore, cannot fall under the auspices of the state designated agency. Regarding development of the state plan using the new "joint-development and sign-off" procedure, advocates in several states have reported that the plan has been developed by state agency staff and handed to the Council chair for approval and signature. I have been told that other state agency staff have threatened not to sign off on a State Plan if it means a loss in control of the Title VII, Part C, funds for the establishment of CILs.

Independence for IL Centers

No issue raised more concern for CIL directors than the channel through which funds flow to CILs. Prior to October 1, 1993, states were given first right of refusal for the funds that were appropriated for CILs. Most states exercised their right and distributed funds to centers through the designated state agency. Center advocates reasoned that CILs themselves must be independent in order to carry out their mission and to meet the requirements of the Act. Center advocates believed that having state agencies administer these CIL-designated funds places centers in a subordinate role to state agencies, which is both unnecessary (in terms of adding an administrative layer) and counter productive to establishing collegial relations. At the same time, some state directors expressed concern that direct funding for the centers would frustrate the development of statewide center networks.

After considerable discussion, a two-tier system was created to give administrative authority for the granting and oversight of CIL funds. A state that contributes an equal or greater amount for the operation of CILS is eligible to receive the Title VII, Part C grant. When the federal appropriation for a state exceeds the state's allocation, RSA will administer and oversee the grant to the CIL through its regional offices. Currently, fewer than 20 percent of the states are in a position to apply for the funds.

Centers in those states are almost universally unhappy with the outcome of the funding stream debate. Many complain that CILs played a central role in securing state funding for centers and that they are now essentially being punished for their efforts. Most CILs familiar with both the federal and state systems contend that state bureaucracies are more cumbersome and intrusive than federal systems.

In several states, the designated state agency has operated one or more centers for independent living, staffing the centers with state employees. According to most participants in the original drafting of Title VII, this clearly was not the intent of Congress. Title VII, Part B was created to establish free-standing centers in which a majority of the governing board members were required to be people with disabilities. Title VII, Part A was to be used to purchase their unique array of services.

A similar problem occurred with the state agencies that serve only persons with visual impairments. Despite language in the Act requiring that persons be provided services without regard to their disability, funds were directed to state agencies for provision of services

exclusively to the blind population. Similarly, many states awarded contracts to agencies providing services to one disability group or to agencies that do not have consumer controlled boards of directors.

IL advocates found this side-stepping of the law to be particularly irritating. Not only had the Act been ignored, but standards developed at the direction of Congress were being disregarded.

To resolve this problem, CILs asked that the Standards (which had been approved by the National Council on Disability in 1986) be inserted into the reauthorized Act. Typically, standards have been addressed through the regulatory process, but IL people felt that placing them in the Act was the best way to assure that the Standards would be taken seriously. The Department of Education must develop indicators for the Standards and apply them when granting funds thereafter.

Early indications are that RSA is doing a commendable job of granting the CIL funds only to legitimate centers in anticipation of the indicators. This is being done, however, in the face of considerable criticism from some state agencies, disability-specific constituencies, and local entities. Even though the appropriation for CILs is only $31.4 million for fiscal year 1993-94, a relatively small portion of a $1.7 billion RSA budget, traditionalists seem intent on wrestling control of the funds away from the IL movement. Fortunately, IL advocates are struggling just as fiercely to keep them.

Trend Toward Consumer Control

The movement toward greater consumer control of the programs funded under the Rehabilitation Act is inevitable. Gaining consumer control of the SILCs and securing co-sign off of the IL State Plan are two of the most obvious indications of change, but improvements have not occurred only in Title VII. Note these other changes:

In Title I, each state is required to establish a state Rehabilitation Advisory Council with numerous planning and oversight responsibilities. Councils are to be consumer controlled, but lack the sign-off authority enjoyed by the IL councils.

Title II requires that the Department set up a Rehabilitation Research Advisory Council to advise the Director of the National Institute for Disability Rehabilitation and Research (NIDRR) on research priorities and develop and revise the long range plan for NIDRR. This Council, however, is neither consumer controlled nor does it have any real decision-making authority.

The National Council on Disability (NCD), with monitoring and evaluation duties relating to several parts of the Act, is for the first time consumer controlled. Changes in the composition of NCD and term lengths of appointees are expected to increase the likelihood that innovative and substantive recommendations will be made to the President and Congress.

Business Advisory Councils, needed for Projects with Industry, are now also required to have individuals with disabilities on them.

Each of the above amendments to the Rehabilitation Act represents a move, albeit a minor one, toward greater consumer involvement in the programs that affect them. After the next reauthorization, perhaps IL Councils will possess the sole authority for sign off on the state IL plans. And the State Rehabilitation Advisory Councils will no longer be merely advisory, but share sign-off authority with the director of the state designated agency.

Imagine exciting projects guided by a consumer controlled Research Council rather than standard academic undertakings driven by university faculty and medical researchers. What if corporate leaders had to actually sit across the table from people with disabilities? How much more quickly they would overcome their own psychological barriers and begin perceiving people with disabilities as colleagues rather than recipients of their largess.

Indeed, it is not inconceivable that consumer controlled councils will oversee all aspects of the Rehabilitation Act and that they will possess the sole authority for the planning and evaluation of Rehabilitation Act-funded programs. Those changes would put our programs at the forefront of an unstoppable movement — a movement which assures that people are in charge of the programs that affect them.

Perspectives on Personal Assistance Services

Photo by Ivan Massar, Black Star

Bob Kafka

American Disabled for Attendant Programs Today (ADAPT) of Texas
Austin, Texas

Part One

Personal Assistance Services (PAS), as defined in the November 1992 position paper of the Task Force on Personal Assistance Services of the Consortium for Citizens with Disabilities (CCD), means one or more persons assisting another person with tasks which that individual would typically do if he or she did not have a disability. This includes assistance with such tasks as dressing, bathing, getting in and out of bed or a wheelchair, toileting (including bowel, bladder, and catheter assistance), eating (including feeding), cooking, cleaning house, and on-the-job support. It also includes assistance from another person with cognitive tasks like handling money and planning one's day or fostering communication access through interpreting and reading services. This all-encompassing definition embodies the cross-disability principles of the independent living movement.

Some disability advocates hope that PAS will become the comprehensive service delivery mechanism for all disability support services, just as the Americans with Disabilities Act (ADA) became the civil rights protection for all disability groups. However, many advocacy groups (disability specific, professional, and issue-oriented groups) approach this new PAS concept with a fair amount of hesitancy, balancing their philosophical commitment to PAS with a sense of the political realities to the degree of change our current system can support.

Another concern to advocates is that although this broadly defined concept of PAS is well known among the tradi-

tional disability leadership in our country, it is not widely understood by the general disability population. The term PAS frequently refers to traditional attendant services used mostly by people with physical disabilities, such as bathing, dressing, feeding, and toileting. The new broader meaning of PAS (as defined by the CCD task force), covering all types of disabilities, has not yet taken hold.

Even the Clinton Health Care Reform proposal uses the term PAS differently in different situations of the plan. In one section PAS is defined as "at least hands-on and standby assistance, supervision, and cuing with activities of daily living . . . " while in the section on tax credits, it is defined similarly to the CCD definition. Using multiple definitions of PAS may have some political advantages but is ultimately confusing.

The reason for the use of multiple definitions by advocates and bureaucrats alike is not simple, but it is based in the history of how PAS developed. Historically, there have been few mechanisms to fund support services, yet a single PAS system has never existed. Our federal funding dictates categorical eligibility criteria for programs based on age or specific type(s) of disabilities. Different groups have won small pots of money to serve their particular population, and limiting the group served has been the main means of limiting the cost of each program. The result is a hodgepodge of support services, some based on age (like the services for people over age 60 funded by Title III of The Older Americans Act), others based on specific disabilities such as the Rehabilitation Act allowance for vocational rehabilitation agencies for people with visual disabilities, or some Title XIX Medicaid funded programs that serve only people with developmental disabilities. Many of these services were hard won, and those served — and their advocates — have strong allegiances to them.

What it appears we are doing now, either as a transitional step or as a politically correct way to protect the current system, is to define as PAS the specific parts that make up our current support system, until a full system of PAS services can be funded.

The new PAS concept challenges these parochial advocacy efforts and forces us to confront what a truly functional support service would mean. It may take a long transition period of frank communication among groups, as well as some combining of support services by function, before we reach an integrated system. Today, the disability community advocates for the whole PAS package when it meets a group's goals, but at the same time groups also advocate to improve their pieces of the PAS system when opportunities arise.

If President Clinton's long term care proposals passed today, they would have a major positive impact on the level of community-based services in most regions of the country. These improvements would advance us towards a comprehensive system of PAS.

Part Two

What follows is an overview of one important segment of the PAS system of services: Community-based Attendant Services. This is the part on which American Disabled for Attendant Services Today (ADAPT) is focusing our efforts.

ADAPT is a grassroots disability rights organization based in Denver, Colorado. ADAPT sprang from the Atlantis Community Inc., which has — for almost two decades — provided community-based attendant services. Advocacy for the rights of people with disabilities has been at the foundation of the Atlantis philosophy. Key to this advocacy has been the belief that people who are affected, people with disabilities, must be the ones to organize to bring about change.

The emotional tenor its members bring to the issue is crucial to ADAPT's role in the development of a comprehensive PAS system. This intensity comes from the fact that many have spent years — even decades — in institutions, because of a lack of alternative community-based services. ADAPT's belief in our right to equality and freedom is strong enough that members are willing to be arrested for civil disobedience in the fight for community-based attendant services. ADAPT uses tactics such as pickets, protests, and "guerilla theater" to bring about changes in public policy.

Currently, over 9 million Americans need assistance with such daily living tasks as dressing, eating, toileting, and housekeeping. When this assistance is provided in people's homes or places of work, it is called community-based attendant services. A recently-released Families USA study found that, in 1992, 64 percent of people needing personal assistance were not able to get it.

Our defacto national long-term services policy opts for institutionalizing people who need assistance, rather than helping them in their own homes and/or communities. Two glaring examples of the institutional bias in our current system are:

(1.) Every state that receives Medicaid funding is required to have a nursing home program but there is no requirement for any home and community services. When community-based services are provided, they are optional services or small waiver programs.

(2.) We spend 82 percent of our federal long-term services funds on nursing homes ($28.4 billion), six times as much as on home and community services ($4.6 billion).

Funding, policies, and regulations all contribute to this institutional bias. Driven at the federal level, this system results in uniformly low amounts of community-based attendant services at the state level.

ADAPT believes that, even without new money, we could begin to fund a national community-based attendant services program simply by redirecting

some of the money now being spent on institutional services into community-based attendant services.

Specifically, the ADAPT position is that the federal government must develop a national community-based attendant services program that meets our daily needs and in the location and manner of our choice by redirecting 25 percent of the Medicaid money that now goes to nursing homes to fund these community-based attendant services. Access to these services must include:

- availability based on functional needs, not medical diagnosis or type of disability;
- availability for people of all ages;
- allowing maximum control of the service by people with disabilities;
- availability 24 hours a day, 7 days a week, with provisions for back-up and emergency services;
- providing people with disabilities options on employer/employee relationships; and
- availability to persons with disabilities on a costsharing basis, if appropriate, and should not be a disincentive to employment.

Part Three

Three major issues surround the delivery of attendant services. First, can an agency-administered model of attendant services contain the principles of consumer choice and control? Most discussions around attendant services assume that the only way to have a true system of consumer choice and control of attendant services is a direct-pay, or individual-provider, model. The debate focuses on whom the employer is, equating employment with control. Another way to look at control is to put aside the concept of employment as the measure of control, and focus on whether the disabled person can select his or her attendant, manage the attendant, and dismiss the attendant. Looking at control in this way allows for a consumer-controlled attendant services program that is either agency-administered or direct-pay to the disabled person.

Second, how are we to deliver "health-related" tasks? These medical tasks are frequently part of the attendant service needs of a growing number of disabled people living in the community. In many states Nurse Practice Acts will not allow an unlicensed person to perform the tasks that are defined as medical. Ignoring the issue or simply stating that our needs are non-medical in nature does not solve the dilemma when someone with a disability requires services, and laws or regulations heavily restrict how such services are provided.

We first must acknowledge that some of our attendant service needs may be medical in nature. This does not mean we need a medical professional to deliver them, but in some instances it may mean we need a nurse or doctor to delegate these tasks to an attendant. State nurse or doctor delegation rules that are flexible enough to allow unlicensed people to perform what traditionally has been seen as "skilled" tasks allow such an arrangement. Our challenge is to push the medical community to recognize that what they see as "skilled" medical tasks, we see as a part of our everyday lives, as "activities of daily living." By expanding our definition of attendant services to include those tasks that can be delegated to an unlicensed person by a health care professional, we keep the concept of attendant services non-medical and include the needs of the growing number of people who use assistance for "activities of daily living."

The last issue is one that permeates the whole delivery system of attendant services — liability. Why do we have this layered, medically-oriented, bureaucratic delivery system of attendant services? People with disabilities frequently explain the licensing of agencies and professionals, the strict guidelines, and the requirements for supervision and/or provision of services as a paternalistic, medically-based system that is trying to over-protect us. Though this over-protection may be partially the cause, I belive the fear of liability has played a much larger role in the evolution of the system than we care to admit. In fact the fear of liability — especially around the delivery of any health-related task — has continued the heavy "medical model" with which we are all so familiar.

There is no simple solution to this problem. Though we can say "let us take the risk," in point of fact, if something "bad" happens we are almost unable, legally, to give up the right to bring legal action. And, we should not promote a system that pits our independence and access to services against our right to hold the responsible party at fault if we are seriously injured. We must continue to advocate and educate the bureaucrats, politicians, and health professionals on our right to take risks. In addition we need to explore ways to alleviate the fear of the economic consequences of providing attendant services by funding risk pools that will not put people at financial or professional risk for performing a service.

Conclusion

The opportunity for significant changes in our whole delivery system of community-based services has never been better. The Clinton Administration has made many promises. It remains to be seen what Congress will pass. Our role is to continue aggressive, no-compromise advocacy to include long-term care in whatever health reform package Congress adopts.

We may disagree on exactly what a comprehensive PAS system should look like, but we must not allow these disagreements to result in the continuation of our institutionally-biased system. The thousands of people locked away in institutions, or who are at risk of going into institutions, no matter what their age or disability, deserve a chance to live in the community with the services they need to lead as dignified and independent a life as possible.

Consumer-Driven Supported Employment: Consolidating Services for People with Significant Disabilities

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Accomplishments in life are often dependent on an individual's ability to access and use a wide range of timely and appropriate support systems. Increasingly, service delivery to people with significant disabilities has attempted to "specialize" in dealing with single segregated aspects of life instead of focusing on the whole person's needs and abilities that will ultimately determine success or failure. The consolidation of "helping" services within a common community-based setting, rather than splintering services across multiple sites (and organizations), is beneficial in meeting the needs of many people with significant disabilities.

Considering the potential value of such consolidation, OSERS' National Institute on Disability and Rehabilitation Research (NIDRR) issued a funding priority to research the combination of supported employment service delivery and support within the community-based independent living center environment (*REHAB BRIEF*, 1992). The Southwest Educational Development Laboratory (SEDL) in Austin, Texas, was selected to begin activities on a National Model for Supported Employment and Independent Living project. The goals of this project were to:

- develop a model of supported employment embodying the independent living philosophy, and
- demonstrate the effectiveness of the model through its implementation in an independent living center setting.

So what's different?

The first question asked by many people deals with the philosophical framework of the project. Although "independent living" is not new, many veteran service providers did not understand what supported employment has to do with independent living, and vice versa. To assist with this understanding,

a concept paper, *Consumer-Driven Supported Employment* (Westbrook & Lumbley, 1988), was developed.

The paper contrasts what had become routine supported employment service delivery with approaches that emphasize and recognize the consumer's wishes and desires. The latter was termed "consumer-driven supported employment."

Exemplary Models Form Base

Additional conceptualization involved an analysis of exemplary supported employment programs that had been identified by NIDRR-funded Regional Information Exchange projects such as the Regional Rehabilitation Exchange (RRX) serving Region VI. This produced a draft model of supported employment service delivery comprised of the "best" components of several different programs. While still untested through implementation, the model did provide a concrete basis for discussion with the staff of a community-based independent living center. The Austin Resource Center for Independent Living (ARCIL) worked with SEDL as the demonstration site implementing the model. Discussions of the draft model with ARCIL staff highlighted areas in which modifications to the original model's design were needed to provide supported employment on the same basis as any other activity area within the independent living center environment.

Holistic Consumer-Directed Approach

Basic to the success of the model was a need to incorporate the consumer-driven supported employment approach that was highly responsive to the desires, likes, and dislikes of the disabled individual. In this context and to be consistent with other "eligibility" requirements within the independent living center, supported employment was based more on the individual's desire to participate than on abstract as-

How Is It Different?

The following describe some of the differences between the more traditional approach and the more consumer-driven supported employment (SE) approach (Westbrook & Lumbley, 1988).

Traditional SE	*Consumer-Driven SE*
Initial Assessment	
Documentation of work history	Determination of desired type(s) of employment
Identification of occupational skills	Determination of desired work characteristics
Determination of previous service record	Identification of consumer-perceived needs to address to obtain desired employment
Plan Development	
Professional develops plan	Joint planning process is used with "other area for resources and accomplishments" provided by consumer
Consumer is informed of best outcome for him/her	Agreement on strategy for goal attainment
Limited alternatives are discussed	Consumer support systems defined and input discussed
Job Placement	
Placement occurs after provider determines "best match"	Jobs developed in response service to consumer's goals for employment
Available job forces selection of available consumer to fill job	Consumer's likes, dislikes, and goals drive the selection of a placement
Training	
Pre-planned timetable determines end of on-the-job training	On-the-job training provided for longer period of time based on consumer needs/desires
Concern with job skill development	Concern with job skill development and shaping the work environment
Closure near the six-month interval	Closure near the 18-month interval
Ongoing Support	
Ongoing support attempts to meet intensive training/re-training needs	Ongoing support involves training/re-training as needed, plus preparation for another job with more responsibility and more pay
More perfunctory	More functional

sessments of skills and abilities. This approach was incorporated into the model by involving the consumer in decisions related to each "phase" of the supported employment process.

The consumer-driven approach reinforces the consideration of an individual's desire to build experiences and skills, some of which may not be directly relevant to employment, prior to undertaking a supported employment position. This holistic approach allows the individual to determine where and when activities to prepare him or her for work are in place — thus addressing some of the affective or emotional aspects of going to work that may keep some consumers or family members from pursuing supported employment (Westbrook, J. and Lumbley, J. 1990).

By allowing any aspect of consumer-perceived "need" to be addressed and dealt with, the model minimizes conflict that may be generated when a more singular, one-minded approach, like traditional supported employment, is used with a significantly disabled consumer. Facilitating access to consumer-desired supported employment opportunities impacts on the "traditional" independent living center in the areas of housing, transportation, counseling, community integration, personal skills, and others.

Organizational Frameworks of Independent Living Centers

Conceptually, the independent living philosophy of community-based independent living centers became the foundation to demonstrate the consumer-driven supported employment approach. ARCIL worked with SEDL in both refining the basics of the model of service and incorporating the supported employment activity area into the mainstream of its organizational activities. Because ARCIL had previously provided some employment-related information and referral activities in the center, supported employment was a needed complement for consumers with more significant disabilities participating in center activities.

Originally, the operating organization activity flow within ARCIL reflected strand activity involving: instructional/transitional services, attendant services, transitional living facility, community resource services, and selected employment-assistance (non-supported employment) services. These strand activities were delivered through the strategies of peer counseling/counseling, information and referral, direct activity, advocacy, and/or networking. These strand activity areas became the framework within which supported employment was added as a component appropriate for Independent Living Plan (ILP) development as shown in Figure 1.

A strength of consolidation in supported employment and independent living is that the ILP, although subject to periodic evaluation and refinement, can generally continue to be "active" for as long as the consumer wishes. While supported employment service delivery has general timeframes for accomplishment and completion, independent living skill development supporting success within the employment situation has the potential to continue as long as desired in the organizationally-integrated design of this model.

It is interesting to note that today some independent living centers providing employment-related services, segregate the activity from other organizational activities. In these cases the people served are not considered

Independent Living Plan (ILP) Development

Strand Activity Areas

Strategies	Instructional/ Transitional Services	Employment Services	Attendant Services	Transitional Living Facility	Community Resource Services	Supported Employment
	← Interface Across Strands, As Appropriate →					
• Peer Counseling/ Counseling • Information and Referral • Direct Activity • Advocacy • Networking	1. Independent and functional life skills development 2. Development of social and leisure options	1. Job readiness 2. Job referral 3. Job club	1. Consumer/ attendant 2. Shared attendant management 3. Attendant management	1. Independent and functional skills development 2. Community resources 3. Attendant care and management	1. Housing referral 2. Transportation 3. Resource utilization	1. Job Club 2. Volunteer program 3. Business Advisory 4. On-the-job training and support
Prerequisites for Supported Employment						
Prerequisites for Supported Employment Placement						

"regular" center consumers being referred to the organization from funding sources only for the supported employment activity. This segregated approach would not promote these individuals' involvement in other center activity. The National Model for Supported Employment and Independent Living was developed to emphasize the value of integrating supported employment with independent living organizational service delivery mechanisms. The model maximizes the independent living activity options in a center rather than diminishing opportunities by creating a separate employment-focused administrative and service activity.

Meshing Support Services

Building upon a framework for supported employment service delivery developed earlier (Szymanski, Buckley, Parent, Parker, & Westbrook, 1988), a service delivery schema compatible with the ILP development framework in the ARCIL setting was developed. The resulting model contained "phases and steps" serving as landmarks in the progression of the consumer-driven, integrated service approach.

From Model to Practice

While a model can be useful, the real test is whether or not it can be successfully implemented to achieve the desired purpose. ARCIL's demonstration activity emphasized the cross-disability orientation of most community-based independent living centers. Through the work of two full-time employment advocates (job coaches), the supported employment activity initially targeted eight consumers with disabilities including long-term mental illness, severe mental retardation, sensory impairment, and physical impairments. Implementation demonstrated the ability of the model within the independent living center setting to meet the diverse needs of consumers with significant disabilities (Westbrook, J., Allison, C., Lumbley, J. and Harris, L, 1991). In time, the ARCIL supported employment program had an "open door" policy allowing consumers to choose supported employment (or competitive employment information and referral) as it was perceived to be appropriate and desirable by the individual.

The value of the project's model was its ability to deal with the factors of life that promote an individual's ability to obtain and maintain community-based employment. In time, every employed individual confronts changes in circumstances of daily living which for the person with significant disabilities may threaten maintenance of supported employment. The orientation of an independent living center is highly compatible, even symbiotic, with the delivery of supported employment services. Initial considerations associated with housing, transportation, daily living skills, and so forth, are important and related to initial success in supported employment. Just as real, however, are challenges that present themselves due to changes in the "plan," e.g., what to do when the bus route to work changes, how to locate a better place to live, and what to do in solving particular social or interpersonal situations. These types of situations are generally not considered to be in the realm of supported employment ongoing/extended services that deal with changes in work routines, changes in work expectations or supervision, the need for increased monetary compensation/work responsibilities, and specific ways to deal with a co-worker "problem." All of these supports naturally blend concerns of independent living with those of supported employment. Blending these supports into the same service delivery structure makes translation to the work environment easier for most consumers with significant disabilities.

Putting the consumer in control of what happens in the supported employment planning and implementation process promotes consumer empowerment. The model would be expected to facilitate compliance with the Rehabilitation Act Amendments of 1992, requiring Individualized Written Rehabilitation Plans to include information about consumers' involvement and control in making the choices reflected in the plan.

How Do You Measure Success?

By the end of the two-year demonstration at ARCIL in 1991, the supported employment activity area had grown to include one full-time coordinator and six job coaches providing services to 38 consumers — seven "stabilized" in their supported employment positions — and 66 others wait-listed to participate in the activity. During the course of the model implementation, staff developed fee-for-service agreements with both the Texas Rehabilitation Commission and the Texas Commission for the Blind, eliminating the use of independent living funds for supported employment activity.

By mid-1993, ARCIL reports its supported employment program has grown to include one full-time job developer in addition to the full-time coordinator, and it retains six employment advocates (job coaches). Employment support services have been requested by 154 individuals with no wait-list continuing to exist. Thirty-two individuals are currently receiving intensive support and 98 have been placed (stabilized) in employment. Of these placements, 42 (43 percent) have been classified as supported employment and 36 (86 percent) of those individuals are continuing to maintain their supported employment. Approximately 6 (15 percent) of the supported employees have moved from their original supported employment placement into one with higher pay and or responsibility. To meet growing needs, ARCIL has opened a satellite office in its catchment area with plans to open a second satellite later this year.

Continuing Needs

There is a need to conduct long-term follow-up with persons placed through the consumer-driven supported employment model to determine if differ-

ences exist in the overall level of satisfaction of these consumers with their supported employment placement. The extent to which this may vary from their more traditional supported employment counterparts is not known currently. Project efforts highlight a need for more study concerning:

- methods to effectively measure consumer satisfaction over time;
- average longevity of supported employees in initial positions;
- degree to which supported employees are experiencing "promotions" in pay/responsibilities; and
- extent to which consumer satisfaction and independent living skills levels are related to the maintenance of supported employment positions.

Evidence from the National Model for Supported Employment and Independent Living indicate a high correlation between consumer satisfaction and career development.

Additional study could also assist in determining the most commonly-experienced independent living needs of consumers with significant disabilities as they prepare for, become involved in, and progress through supported employment opportunities. Making such needed assistance available as a part of the supported employment delivery system — hopefully, in collaboration with community-based independent living centers — greatly enhances the overall effect on the "whole" person and resulting level of satisfaction of many consumers. NIDRR's National Model for Supported Employment and Independent Living clearly demonstrates that such consolidation of efforts is possible and can result in a viable and effective method for providing major support services.

Summary

NIDRR's National Model for Supported Employment and Independent Living demonstrates that community-based independent living centers can effectively and efficiently render a type of supported employment assistance that goes beyond routine supported employment service delivery. While initially this type of activity may present accounting and managerial challenges to the center administration, many consumers with significant disabilities are both interested in and capable of benefitting from the consumer-driven supported employment approach. Linking independent living and supported employment activities makes good sense in meeting the needs of the whole person with significant disabilities.

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The Effects of Insurance Benefits Coverage: Does It Affect Persons with Spinal Cord Injury?

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The provision of health care rehabilitation and independent living services for persons with long term needs, such as persons with spinal cord injury (SCI), has become exceptionally costly. Some studies suggest that lifetime costs for persons with SCI range from $210,400 to $751,900 (Pope & Tarlov, 1991). Because of the need to curtail costs associated with rehabilitation, increasing numbers of persons with SCI are forced to choose between paying for their uncovered health/rehabilitation benefits or not receiving the services they need to maintain health and to live independently (DeJong et al., 1993). Indeed, when insurance coverage is lacking or inadequate, persons with SCI and their families not only face financial catastrophe but also may not receive necessary care when serious health problems arise (DeJong et al., 1989).

Several concerns can be raised about the appropriateness of current health/rehabilitation insurance coverage for persons with SCI. Most medical insurance plans do not appear to address adequately the special needs of persons with major physical disability such as SCI who wish to live independently in their communities. In fact, insurers may use the criterion of "medical necessity" to ration health care coverage. In contrast, advocates for the independent living (IL) movement have long argued that access to these resources (e.g. personal care assistant (PCA), adaptive equipment, accessible transportation and modified housing) can reduce reliance on institutional care and promote economic and social self-sufficiency. Similarly, the nature of personal assistance services and the range of transportation options have been linked theoretically and empirically to enhanced psychological and social independence (Bowe, 1980; DeJong & Wenker, 1983; Nosek et al., 1987).

Although several authors have emphasized the importance of examining how insurance coverage affects adequacy of benefits and services provided for persons with disabilities wanting to live independently, studies designed to address this issue are rare. The current study, funded by the National Institute on Disability and Rehabilitation Research (NIDRR) from 1990 to 1993, examined the potential effects of rehabilitation insurance coverage on post-discharge functional and psychosocial outcomes of persons with SCI.

SCI persons sponsored by catastrophic payors (Michigan Automobile No-Fault or Workers' Disability Compensation), were thought to receive more extensive benefits coverage and resources to address their IL needs. In comparison, SCI persons sponsored by Michigan Medicaid and private payors were assumed to receive fewer benefits and resources. Researchers were particularly interested in knowing if persons with SCI who received more benefits and resources would exhibit better post-

outcomes when compared to those who received fewer benefits and resources.

Scope of the Research

Our study included 170 persons with SCI with dates of injury from 1985 to 1990 and of ages between 17 and 65. All subjects were two or more years post-discharge from initial inpatient rehabilitation, and received their initial inpatient rehabilitation at one of two Southeastern Michigan rehabilitation centers: the Rehabilitation Institute of Michigan (RIM) or the University of Michigan Medical Center (UMMC). RIM, which is affiliated with Wayne State University, is located in Detroit and serves primarily an urban, non-Caucasian population. UMMC provides rehabilitation services to a large group of mostly Caucasian patients outside of the Detroit area who live in diverse settings (affluent suburban areas and rural areas).

The sample was comprised mainly of males (85.9 percent), and the average age was 34.6 years. The time between injury and interview varied from two to seven years, with an average of four years.

Assessing Independent Living Benefits

The Benefits Coverage Inventory (BCI) was used to assess rehabilitation/IL benefits received during the two years following discharge from inpatient rehabilitation in five areas: housing, personal care assistance (PCA), transportation, outpatient therapies (e.g., physical therapy, occupational therapy, vocational rehabilitation), and equipment (durable and nondurable). Durable equipment included items such as wheelchairs, braces, and hospital beds, while other equipment included communication devices (e.g., computers, environmental control units, adaptive telephone equipment), and bathing equipment (Tate & Daugherty, 1992). The BCI asks patients about benefits and resources received and perceived

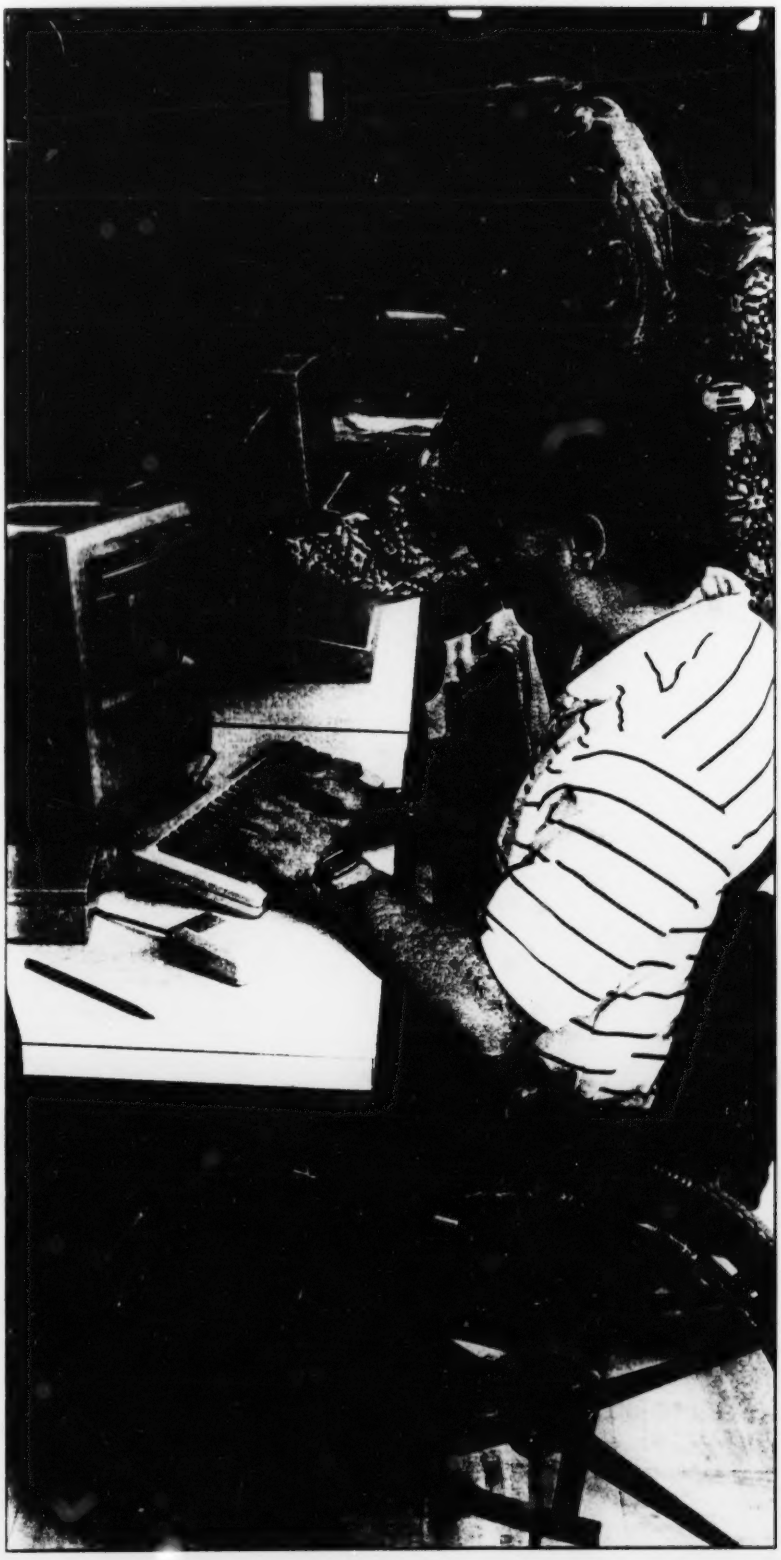


Photo courtesy Ball State University

as necessary as well as who paid for these items (i.e., insurance, self, or other). Only items estimated to cost $100 or more are included in this inventory. BCI scores take into account the approximate cost of each item within an area.

Assessing Functioning in the Environment

The Craig Handicap Assessment Reporting Technique (CHART) was used to assess functioning in the environment for persons with SCI. The CHART measures the degree to which physical impairments may result in handicap for the SCI person in relation to his or her social environment (Whiteneck et al., 1988). A handicap is experienced when changes in physical status or functioning lead to altered performance of activities of daily living, which, in turn, interact with environmental factors to produce limitations of social role performance (Whiteneck et al., 1992). CHART handicap is measured in five domains: physical independence, mobility, occupation, social integration, and economic self-sufficiency. For this study, the following activity outcome measures were used based on CHART items: Physical Activity (based on CHART's mobility scale items describing hours out of bed per day, days out of the house per week, and nights spent away from home per year); and Work/School Activities (based on CHART's occupational scale items describing hours per week in gainful employment and in educational activities or retraining).

Assessing Distress and Self-Esteem

Psychological distress has been reported to be the most significant indicator of post-discharge adjustment among SCI patients (Shadish et al., 1981). The Brief Symptom Inventory (BSI) was used to assess post-discharge distress; it evaluates distress based on a variety of symptoms: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism (Derogatis & Spencer, 1982). A general index of distress is provided by the BSI/GSI or Global Severity Index. A score of 65 or greater on the GSI or any of the subscales suggest abnormal distress.

Rosenberg's Self-Esteem (RSE) scale assesses general feelings of self-acceptance and self-respect (Zemore & Shepel, 1989). This sense of personal worth is an indicator of effective adjustment to SCI. Self-esteem is viewed also as a resource that helps individuals withstand the negative effects of the injury (Hobfoll & Walfisch, 1984). Perceived independence, provision of one's own transportation, assistance needed, and living arrangements are significantly related to one's self-esteem.

Benefits as a Function of Payor and SCI

Neurological classification statistical analyses supported the fact that SCI subjects with catastrophic coverage obtained significantly more total benefits than did subjects insured privately. The amount or extent of benefits and resources received to cover independent living needs was also found to be dependent on the individual's neurological classification. Persons with complete quadriplegia received more resources than those with other diagnoses.

The Effects of Payor and SCI Neurological Classification on Functional Activity and Psychosocial Outcomes

In general, post-discharge physical activity was not found to be related to type of payor for rehabilitation and independent living services but work activity was. Catastrophically-sponsored persons with quadriplegia were least likely to engage in work/school activities when compared to those of similar neurological grouping sponsored by Medicaid or by private insurance. Persons sponsored by private insurance were most likely to be engaged in work and school activities.

Predicting Physical Activity and Work/School Outcomes

Total extent of benefits and type of benefits received were not significantly associated with post-discharge physical activity. Physical activity was most strongly associated with subjects' demographic factors (i.e., age, race, marital status, education), neurological status, and self-esteem. Younger, Caucasian, single, more educated subjects with less severe injuries who paid for their own IL resources and who had greater self-esteem were likely to be more physically active. Type of benefits received was also associated with work/school activities. Subjects with greater access to transportation were more likely to report these activities. Furthermore, younger subjects with incomplete injuries who were sponsored by private insurance and had a greater time interval since injury were more likely to report being engaged in work/school activities after discharge.

Predicting Distress and Self-Esteem After SCI

Psychological distress after SCI was predicted by extent of benefits or resources received, type of payor, and subjects' education. Those sponsored by Medicaid, with less than high school education, and who reported receiving more benefits (either paid by a combination of sources or insurance only) were more distressed. Similarly, those who received more benefits exhibited lower post-discharge self-esteem. Particularly, those receiving more services were more likely to exhibit lower self-esteem. In contrast, those receiving communication equipment had higher self-esteem.

Does Receiving Greater Benefits Result in Poorer Outcomes?

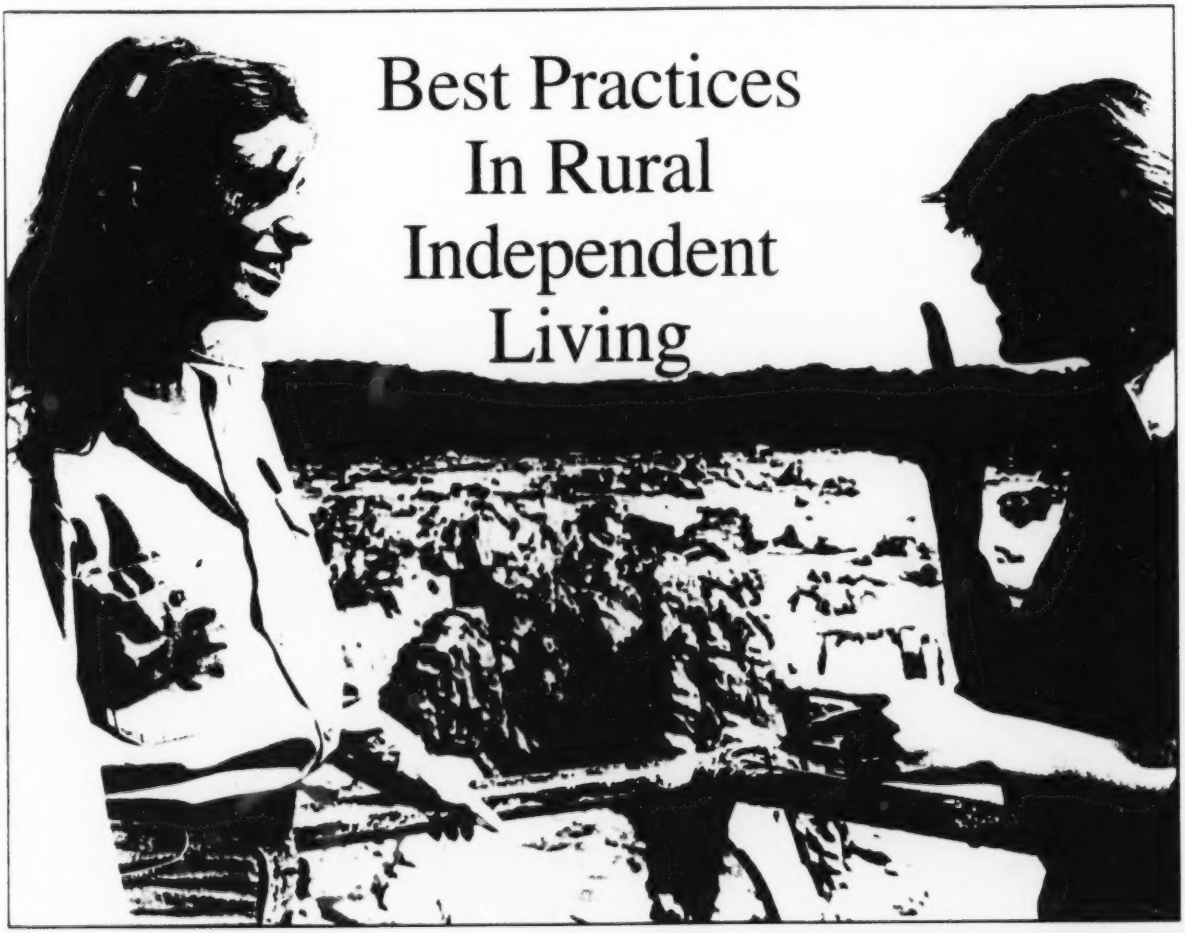
Although some of our findings seem to point in that direction, that is not necessarily so. Our study did not take into account causality. Rather, it looked at an association between factors. Second, it is expected that those who are more severely injured may exhibit poorer outcomes. This was clearly supported by the consistent association of neurological classification with extent of benefits received. Third, in interpreting these findings, the payor may represent a proxy variable for other factors such as subjects' education, previous work history, and other socio-demographic factors that best explain work/school activities after SCI. Benefits were most significantly associated with the psychosocial outcomes and less associated with the physical functional ones. Subjects who received more benefits reported higher distress and lower self-esteem. Extent of benefits received after rehabilitation was not an important factor in predicting physical activities. Yet, subjects engaged in work/school activities were more likely to have received transportation benefits and were also more likely to have an incomplete injury. These findings are helpful in understanding the association between receiving transportation benefits and higher distress. To a certain extent, these relationships were expected when one considers distress as a normal coping response to dealing with functional limitations in an active social and work environment. From a theoretical perspective, receiving benefits may relate to one's perception of dependency on others and lack of control over one's life. This viewpoint is further reiterated by the fact that privately sponsored subjects who received fewer benefits exhibited higher self-esteem. This strongly suggests that control of one's financial destiny may indeed relate to lower levels of distress and greater self-esteem. Medicaid-sponsored subjects, who reported the lowest levels of income prior to injury, experienced greater distress even though they received approximately the same level of benefits as private subjects. Furthermore, among Medicaid and catastrophic sponsored subjects having to justify the need for insurance covered benefits may have contributed to their perceptions of low self-esteem, of having significant physical impairments, and of dependency on others. Similarly, feeling less able to work or engage in school activities may have encouraged further distress. These findings are notably consistent with those of Fuhrer et al. (1992) who argue that greater perceived control and positive self-perceptions of physical health are strongly associated with greater life satisfaction, adjustment, and decreased depression in persons with SCI.

Our findings make a special case for those who received benefits paid by other sources, such as under the State Vocational Rehabilitation (VR) agency. These subjects, although receiving benefits paid by others, reported higher self-esteem. This may be attributed to the high value given to work in society. Thus, being recognized as potentially able to work could have functioned as a boost to self-esteem. This line of thought was further supported by the fact that those with higher self-esteem also reported receiving more communication equipment (i.e., computers, environmental control units) paid for mostly by insurance. In contrast to durable equipment (i.e., hospital bed, hoyer lifts) which suggest dependency, communication equipment is more suggestive of independence and motivation to engage in productive activities. Participating in these activities appears to renew one's sense of self-worth. Similar findings have been reported by Green and associates (1984) in a study of self-concept among persons with long-term SCI. In his study, more productive persons were characterized by effective social and intellectual functioning, and high self-esteem and assurance.

While most of our findings did not support the assumption that persons with more extensive coverage would exhibit better outcomes, they certainly imply possible changes for the current benefits system. Several factors need to be considered when deciding how benefits can be helpful to persons with disabilities: (1) a voucher system that allows persons with disabilities to make actual choices and to be responsible for the benefits they chose; (2) educating persons with disabilities on how to use effectively benefits according to their needs; and (3) changes in current income programs associated with each payor's standard coverage to boost motivation to pursue work/school activities. This is especially true for those sponsored by catastrophic payors and Medicaid and those who begin receiving income benefits after discharge. In this respect, disability income may have contributed to a decreased interest in work/school activities. This issue was not directly addressed by our study since income benefits were not included in our data assessments. Yet it remains a most important issue for future studies in this area.

Concrete vocational plans made during the early stages of rehabilitation may enhance motivation for both functional recovery and post-discharge psychological adjustment. In this respect, exposing persons with disabilities to return to work and vocational programs early during the inpatient rehabilitation phase can be helpful. Policies that merely emphasize the provision of income benefits after injury should be exchanged for policies that more aggressively prepare persons with disabilities to become productive in society. Providing business with further financial incentives to hire and train persons with disabilities is an important step in facilitating work/school activities after SCI.

Learning From The Experts:



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Over 11 million Americans living in rural areas have a chronic or permanent disability (Barker, O'Neill, & Karp, 1984; Matheson & Page, 1984). This represents a higher per capita rate of disability than exists in metropolitan areas (Kraus & Stoddard, 1989). While people with disabilities in rural areas typically have far fewer opportunities to receive health care and independent living (IL) services than do their counterparts in urban areas (Nosek, 1992; Potter, Smith, Quan, & Nosek, 1992; Rojewski, 1992), few want to move to an urban environment and leave their familiar surroundings and culture (Carney, 1992). This is particularly true for Native Americans living on reservations (Clay, 1992).

Rural communities have many strengths. The social fabric of rural communities often emphasizes a strong extended family structure lacking in urban areas. Disabled people raised in this culture may prefer to remain in their home community and receive assistance from friends and relatives—rather than moving to the city to live in a highly regulated public housing program and receive similar assistance from nurses, aides, and social workers. Thus, the cultural norms and expectations of rural people with disabilities are often quite different than those of people from urban areas.

Further, an increasing number of IL service options are becoming available in rural areas (Richards & Smith, 1992). In 1986, several independent living centers (ILCs) formed the Asso-

ciation of Programs for Rural Independent Living (APRIL) to address rural service inequities and promote independent living among rural residents (Gonzales, 1992). Seekins, Ravesloot, & Maffit (1992) identified 76 ILCs serving rural areas in 48 different states. Researchers are also engaging consumers and service providers from rural communities in efforts to formulate an agenda for rural rehabilitation research and services (Jackson, Seekins, & Offner, 1992; Offner, Seekins, & Clark, 1992).

To successfully serve people with disabilities in rural areas, however, Gonzales (1989) notes that service providers must be particularly resourceful in identifying existing or potential resources. Further, they must be willing to travel to remote areas, often guided only by the direction, "Turn right at the skull hanging on the fence post, past the dirt road with no sign" (p. 5). Similarly, Offner (1990) suggests that rural service delivery personnel must be willing to use innovative and often untraditional service delivery approaches. Thus, it is critical to learn from exemplary programs that are currently demonstrating excellence in service delivery (Olander, Walker, & Prazak, 1990).

Innovations in Rural Independent Living Project

With funding from OSERS' National Institute on Disability and Rehabilitation Research, the Innovations in Rural Independent Living Project was initiated in 1990 to: (1) identify exemplary rural IL programs that have successfully assembled unique resources to increase disabled citizens' potential to live independently; (2) verify the effectiveness of these programs and develop strategies to replicate these practices in other areas for similar groups; and (3) disseminate information from this nationwide project to other rural IL programs.

The three-year project was conducted as a collaborative effort of the University of Kansas Research and Training Center on Independent Living (RTC/IL), the Research and Training Center on Rural Rehabilitation Services (RTC: Rural), and the Association of Programs for Rural Independent Living (APRIL).

Initially, project staff conducted an extensive review of the literature on the needs of people with disabilities in rural communities and viable rural service delivery approaches. The APRIL Board of Directors were then asked to rank the importance of issues that might be solicited for Best Practices Awards. Their recommendations provided a framework for the topics to be studied throughout the project. During the first year, the project targeted accessibility of commercial and public buildings, accessible transportation, affordable and accessible housing, community support and responsiveness to independent living, disability rights and advocacy, peer support, and personal assistance for independent living. In year two, the project focused on alternative funding strategies for IL services, interagency networking, strategies to reach minority populations, leadership development, home accessibility modification, public awareness about IL philosophy, and health promotion activities. The project's sole focus in the final year was on successful strategies used in rural communities to implement the Americans with Disabilities Act (ADA).

Each year 5,000 announcements describing the Best Practices in Rural Independent Living Program were published and distributed to independent living programs, National Organization on Disability community partners, and other disability advocacy organizations throughout the United States. Personal telephone calls were placed to the independent living coordinator of each state office of vocational rehabilitation and regional ADA technical assistance programs to solicit nominations. In addition, program staff distributed announcements at a wide variety of regional and national conferences on disability, independent living, health promotion, and rural services.

Each spring the program's staff and APRIL Board of Directors reviewed all applications and nominations received to identify potentially effective strategies within each topic area and select programs to participate in site visits. In turn, program staff visited 15 to 18 different programs each year to learn more about the innovative practices being used by these exemplary programs. From these programs, 5 to 7 were selected each year to receive an award and were invited to describe their innovative programs at the annual Rural Rehabilitation Conference (Common threads: Weaving together rural resources for people with disabilities) held in Missoula, Montana.

Descriptions of 83 different innovative program efforts have been cataloged in a Rural Options Database. This free-standing computer program, contained on a single 3.5 inch computer disk, can be run on any computer that uses MS-DOS version 2.0 or greater. The database provides access to information about each program or service option and is capable of sorting program efforts by topic of interest. Each program or service option includes a narrative text that evaluates the program and describes contextual features that may affect its successful implementation. The database also includes information about a contact person, telephone number, and mailing address for each program. In this way,

anyone wishing to replicate a program's effort will have direct access to the experts that originally designed the service option.

1991 Award Winning Programs

Access Alaska (Fairbanks, AK) for their approach to promoting accessible housing

Home accessibility is a crucial problem for many people with disabilities. The Independent Living Center in Fairbanks established a partnership with the local carpenter's union. Union carpenters volunteer their time and expert labor to make home access modifications for people with disabilities. Union volunteers are then "moved up" on the work list by the union's business manager for paying jobs. In the program's first year, over 60 home access modifications were provided for people with disabilities. Initial funding to establish a revolving fund to purchase building materials was provided through a $2,000 grant from the Easter Seal Society. Access Alaska subsequently received funding from the state of Alaska to expand the program statewide.

The Easter Seal Society of Iowa (Des Moines, IA) for promoting community support

The Farm family rehabilitation management (FaRM) project assists Iowa farmers by providing support and access to rehabilitation technology to allow them to continue living and working on their farms after they become disabled. Program components include: (a) a peer technical assistance network of disabled farmers who are successfully working their farms; (b) an ingenuity network of volunteers to fabricate assistive devices, generate ideas, and obtain materials; and (c) a Mobil Rural Technology Unit to construct assistive devices on site at the participant's farm. Over 350 disabled farmers received assistive devices to allow them to continue farming in the project's first five years of operation.

Southeastern Minnesota CIL (Red Wing, Winona, and Rochester, MN) for promoting disability rights and advocacy

SEMCIL established consumer-driven access and advocacy commissions in three rural Minnesota communities. Each commission, composed entirely of persons with disabilities, is designed to provide opportunities for persons with disabilities to: (a) learn how to advocate for themselves at local, state, and national levels; (b) take an active role in their community by advocating for positive changes; and (c) improve the accessibility of their own community and enhance the integration of people with disabilities. Local impacts include creation of curb cuts, expanded transportation services, enhanced disability awareness of bus drivers and public officials, and access modifications in public buildings and public transportation.

Access Hibbing (Hibbing, MN) for promoting public building accessibility

Conservative business owners and public officials often actively resist change, particularly if they believe they are being "forced" to change. Therefore, access advocates in Hibbing first created an access guide for public and commercial building and focused on enhancing community awareness about accessibility. In the process, they enlisted participation of the local Chamber of Commerce, newspaper, service organizations, and building officials in promoting the message that access is a benefit to everyone in the community. Information and technical assistance were provided to business owners, which resulted in access modifications in numerous commercial buildings, and the City Council passed a resolution to make Hibbing barrier free.

New Vistas ILC (Raton & Santa Fe, NM) for promoting accessible transportation

The only form of public transportation in many small, rural communities is the ambulance service operated through the nearest hospital, thus, a one-way ride can cost over $100. Taxi and bus service is typically unavailable, so private transportation is the only possibility. Yet, many disabled persons do not have personal transportation. An outreach worker from New Vistas ILC collaborated with a local Raton church to obtain federal funding to purchase a lift-equipped van to serve disabled and elderly residents in Raton. The church secretary maintains the schedule for the van and the van is insured by the church. All van drivers are volunteers. In return, the church uses the van to transport disabled and elderly members to Sunday services.

Vision Northwest (Portland, OR) for their statewide peer support program

Vision Northwest coordinates peer support programs for people who have lost their vision as adults. Thirty-four support groups, serving over 500 members, operate throughout the state. Vision Northwest maintains a toll-free telephone number for support group leaders and conducts monthly support group leader training sessions. Support group leaders guide discussions about both the physical and emotional aspects of coping with vision loss. Each peer support group also operates separate support group sessions for friends and family members.

Rhode Island Housing and Mortgage Finance (Providence, RI) for their approach to promoting personal assistance for independent living

Rhode Island (RI) Housing and Mortgage Finance is responsible for 9,627 Section 8 housing units, located in 72 separate developments. Their foundations of senior health "Residence Services" program was initially funded by a grant from the Robert Wood Johnson Foundation to expand in-home assistance services to disabled elders living in public housing projects. RI Housing established a one million dollar endowment to be used as matching funds for in-home assistance. Participating building managers similarly contribute $10,000 each year for in-home assistance services for disabled elders living in their building. On-site services include homemaker services, financial management, information and referral, and attendant services.

1992 Award Winning Programs

Alpha One Center for Independent Living (South Portland, ME) for their innovative funding strategy

Staff and consumers from Alpha One worked with the Finance Authority of Maine to create a five million dollar "revolving" fund to provide low interest, long term loans for individuals with disabilities and businesses to purchase technological aids or adaptive equipment. Loans are administered through Alpha One's adaptive equipment loan program. Examples include vehicle hand controls, motorized wheelchairs, wheelchair lifts, or any other adaptation that creates access to opportunities for persons with disabilities. In addition, the Center operates a consumer-run assistive technology and

wheelchair repair business (Wheelchairs Unlimited) as a wholly owned, for-profit subsidiary. Profits from Wheelchairs Unlimited are used to fund IL services and advocacy efforts offered by Alpha One.

Disabled, Information, Awareness, and Living, Inc. — DIAL Northwest — (Sparta, NJ) for leadership development

DIAL Northwest used a community organizing approach to recruit and train people with disabilities from rural Warren County in leadership and advocacy skills. This effort was in response to many county residents' complaints about isolation and lack of services. The ILC used volunteer college student interns to organize and conduct the training sessions. They established a telephone tree to inform interested consumers about meeting times (each person called five others who in turn called five more) and targeted the local para-transit system's policy on ride priorities as their first community-change effort. They successfully networked with existing social service agencies to gain support for the creation of an Office on the Disabled within Warren County (one of only two counties in New Jersey without such an office). Within the first year, the coalition had grown to 110 members; the county para-transit system had modified its policies; and several members of the advocacy group had been charged with the task of guiding the development of the new Warren County Office on the Disabled.

Disabled Citizens Alliance for Independence (Viburnum, MO) for their home accessibility modification program

Since 1980, DCAI has provided home modifications (primarily ramps) to persons with disabilities who reside in seven southeast Missouri counties. People with the financial resources to build a ramp are given technical assistance, including blueprints. Program staff also secure funding for modifications through vocational rehabilitation or Title VII Part A funding for some consumers. However, DCAI will also build ramps for persons who are not eligible for funding through other sources. DCAI staff have established a network of resources that include pallet, post, and wine vat mills located throughout their service area. Mill owners donate rough-cut oak timber for the ramps and, whenever possible, additional materials (bolts, nails, paint) are obtained through NAIER of Galesburg, IL (corporations donate surplus materials to NAIER, who distributes the materials to non-profit groups that pay a yearly membership fee to NAIER). This greatly reduces the cost of each ramp. DCAI staff design and build the ramps in sections and then deliver and install them on site. Volunteers and business donors are honored at an annual awards dinner.

Head Injury Association of Kansas (Shawnee Mission, KS) for their health promotion activities

The Head Injury Association created the Kansas Head and Spinal Cord Injury Prevention Program to educate youth about the causes and consequences of brain and spinal cord injuries and promote risk-management behavior. The campaign is modeled after the national program, Think First. Program staff and volunteers conduct one hour, multi-media presentations for teenagers and young adults in rural public and private secondary schools throughout Kansas. Professional speakers show slides and discuss the anatomy and physiology of the human spinal cord and brain, provide statistics on the incidence of injuries to youth, and screen "Harm's Way" (an action-oriented, award-winning film dealing with the topic of risk management). In addition, teens hear from young Kansans who have experienced brain or spinal cord injury about simple things they can do to reduce their chances of injury.

League of Human Dignity (Lincoln, NB) for their alternative funding strategy

Mobility Options, a for-profit division of the League of Human Dignity, provides vehicle modifications for transit authorities and persons with disabilities in a four-state region. Mobility Options has a staff of three full-time and two part-time employees and serves as a dealer for over 300 major manufacturers of conversion equipment and supplies. Vehicle modifications include floor drops, power lifts, ramps, door openers, and hand controls. The ILC obtained funding to purchase Mobility Options through bank financing and a HUD loan from the city's economic development program. The ILC makes monthly loan payments and plans to complete repayment of all loans within five years. Once the loans have been repaid, all profits from Mobility Options will be used to fund advocacy and services provided by the League of Human Dignity.

LINK, Inc. — Living Independently in Northwest Kansas — (Hays, KS) for their interagency networking efforts

LINK has been instrumental in developing a cooperative, coordinated effort to provide accessible public transportation for all persons (including the elderly and those with disabilities) in rural Ellis County, Kansas. Prior to their efforts, various agencies had separate vans and differing hours of operation. Each agency provided limited services to its specific target popula-

tion with no coordination between organizations. Staff from the Kansas Department of Transportation (KDOT) became concerned with continued requests for funding for new vehicles, when existing vehicles were often underutilized. They required all KDOT-funded transportation providers to participate in a coordinating council to organize a single public transit system for the county, or risk losing KDOT funding. The Council selected a single agency to assume the cost and responsibility of dispatching services and established routes and schedules that were responsive to the needs of disabled consumers. The new system was successful in expanding the hours of operation beyond what any of the previous independent transportation providers had offered and created an accessible fixed route and demand response service that serves the entire county. In the first year of operation, the new system provided 34,000 rides throughout Ellis County.

1993 Award Winning Programs

Center for Independence (Grand Junction, CO) for ADA implementation

The Center for Independence (CFI) serves a 13 county region within Colorado's western slope. CFI reaches out to every segment of the community through marshaling the resources of consumers, residents, and public entities in order to actualize ADA legislation within rural Colorado. CFI educates the community on the Americans with Disabilities Act (ADA) by sponsoring workshops and presentations. This rural ILC was able to create a new, full-time staff position for ADA implementation by securing a volunteer paid by VISTA. CFI also assists consumers, businesses, and public facilities with ADA compliance through providing ADA training and consultation. For example, the public library and fifty-six of the sixty-one regional polling precincts are now accessible due to CFI advocacy and consultation. CFI is also working with city officials to increase accessibility on a large number of east-west and north-south streets by designing a bike path that includes curbcuts wide enough for wheelchairs.

IMPACT Inc. (Alton, IL) for ADA implementation

IMPACT is a nonprofit organization founded in 1985 by persons with disabilities in Madison and the surrounding counties. IMPACT educates rural citizens about the needs of their citizens with disabilities and provides training on proper ADA evaluation procedures. IMPACT assists municipalities, businesses, schools, and other organizations in southwestern Illinois with ADA compliance. The organization will evaluate their employment practices, existing facilities, construction plans, and program accessibility and recommend the needed changes including compliance dates. After assessing buildings, parks, and programs for accessibility, IMPACT develops and disseminates a self-evaluation and transition plan. For instance, IMPACT contracted with the city of Alton to provide ADA consulting services for inspecting all of their building permits and to oversee their curb cut program. IMPACT has also given 50 presentations at city and county meetings and provided 35 Title II ADA consultations for local governments. IMPACT has received a state grant to provide smaller rural communities with ADA consulting services. The organization will assist public and private organizations with locating and applying for funding sources which facilitate ADA compliance.

Services for Independent Living (Columbia, MO) for ADA implementation

Services for Independent Living (SIL) serves 25 rural counties in mid-Missouri. SIL provides ADA education and training through developing and facilitating a network of community-based and consumer-directed coalitions. Facilitating peer support for persons with disabilities is an additional benefit that has resulted from a consumer lead coalition-based system to increase accessibility. SIL assists coalitions in networking with other community resources, statewide ADA resources, and with each other. Each of the chapters is responsible for assisting their local governments, schools, and businesses with ADA assessments and implementation plans. In addition, SIL conducts ADA surveys and provides compliance recommendations for public and private organizations.

HASL—Handicap Awareness and Support League Inc. (Grants Pass, OR) for ADA implementation

The Handicap Awareness and Support League (HASL) is an Independent Living Center serving a five-county region. HASL currently has an access committee and an ADA certified staff member for providing training to public officials and business owners. HASL works with local governments in evaluating government-owned buildings, sidewalks, parking, and parks for compliance with the ADA. HASL has assisted local public officials with applying and receiving Community Development Block Grants from the state to bring public buildings into ADA compliance. HASL also assists businesses in conducting evaluations and writing up recommendations. HASL not only conducts ADA surveys but provides a follow-up report that identifies the barriers, solutions, and a

proposed time-frame for correction. In celebration of the National Barrier Awareness Day, HASL placed public officials, community leaders, and business people in wheelchairs on a scavenger hunt to experience first-hand accessibility barriers.

Prairie Freedom Center for Disabled Independence (Sioux Falls, SD) for ADA implementation

The Prairie Freedom Center is an Independent Living Center that is responsible for ADA implementation within a five-county region in eastern South Dakota. The Center organizes meetings with interested consumers, disability organizations, and civic groups and provides them with education or training on ADA specifications. These established community teams assist the Center with setting up informational meetings and other advocacy tasks within their community. The Center contacts city and county governments to discuss ADA requirements and requests a copy of their ADA implementation plan. The Prairie Freedom Center also conducts ADA facility review for businesses and other service providers. The Center staff works directly with building and inspection offices for consultation needs and as an available referral resource on ADA requirements.

Breaking New Ground (Purdue University, West Lafayette, IN) for ADA implementation

Breaking New Ground (BNG) is a USDA National AgriAbility Project directed towards rural communities, county/city government leaders, agricultural businesses, rural professionals, and Cooperative Extension Service personnel. Through networking within these systems, BNG assists rural communities with education, training, and implementation of the ADA. The agency has provided over 50 ADA accessibility assessments within rural communities; given ADA compliance checklists and ADA resource packets to over 200 extension agents; and presented ADA accessibility training to over 500 rural professionals. BNG has developed a number of resources that can be obtained by request: (1) a video on compliance guidelines for county extension offices and 4–H fairgrounds; (2) a video that provides an overview of the ADA and practical low cost solutions for small business; (3) resource packets and accessibility checklists specifically targeted for rural and agricultural businesses, county extension agencies, and 4–H fairgrounds; (4) a leader's guide for rural professionals to organize meetings on the ADA; and (5) an educational publication for rural businesses and a newsletter for farmers and ranchers with physical disabilities. In addition, even though churches are exempt from ADA, BNG has developed an accessibility checklist and other materials for interested churches concerned about meeting the needs of persons with physical disabilities.

The Rural Options Database includes information about these award winning programs along with information about many other innovative strategies used by other rural programs. By sharing the experience of these experts with other service providers and advocates, the project hopes to expand the resources available to people with disabilities throughout rural America.

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Improving Management Effectiveness in Independent Living Centers through Research and Training

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Introduction

The independent living movement emerged in the late sixties and early seventies as people with disabilities began to demand a greater role in decisions about services that affected their lives. The first independent living center (CIL) was begun in Berkeley, California in 1972, followed later that same year by establishment of centers in Houston and Boston. These early efforts were characterized by a mix of residential and support services that would appear to be very different from the independent living centers that many of us are familiar with today. What was common to these efforts and what has been carried forward to the present was the substantive role that people with disabilities played in organizing, administering, and operating these early programs.

The number of independent living centers grew slowly between 1972 and 1978 as people with disabilities struggled to find funding to develop programs and services. In 1978, with establishment of Title VII of the Rehabilitation Act Amendments, the funding needed for development of independent living centers nationally finally became available. Today, there are some 240 independent living centers (ILRU, 1993) that meet the criteria established by the National Council on Disability in 1985 and codified through inclusion in the 1992 Amendments to the Rehabilitation Act. These criteria include: offering the four core services of information and referral, peer counseling, independent living skills training, and individual and systems advocacy; serving a cross-disability constituency; and having a majority of persons with disabilities on governing boards and in decision-making and service delivery staff positions.

Efforts to Document Management Research and Training Needs

As with all new fields, there were few sources of information available to assist people with disabilities in initiating independent living programs and services during the early days of the movement. Although information on independent living and disability rights could be obtained from a number of sources around the country, including the CIL in Berkeley, Boston CIL, and Cooperative Living in Houston, there was no mechanism in place for collecting and disseminating information nationally. In 1977, leaders of the Cooperative Living Program at The Institute for Rehabilitation and Research (TIRR) in Houston established the Independent Living Research Utilization (ILRU) Program to serve as a national center for information, training, research, and technical assistance in independent living.

In 1977, ILRU obtained funding from the Rehabilitation Services Administration (RSA) to develop a definition of independent living that reflected the values and perspectives of people with disabilities who were working to establish independent living services. Many leaders in the emerging independent living movement were involved in developing and refining the definition of independent living, including Ed Roberts, Judy Heumann, Max Starkloff, Fred Fay, and Lex Frieden. The definition that was developed and that is now used widely established independent living as *"Control over one's life based on the choice of acceptable options that minimize reliance on others in making decisions and in performing everyday activities. This includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, and making decisions that lead to self-determination and minimization of physical or psychological dependence on others"* (Frieden et al., 1979).

Since 1977, ILRU has been engaged in conducting research on independent living and disseminating the results of that research through training, technical assistance, and materials development and dissemination. In 1985, ILRU was funded by the National Institute on Disability Rehabilitation and Research (NIDRR) as a research and training center in independent living. With the competitive renewal of NIDRR funding in 1990, the activities of the research and training center focused on management issues specifically. Also, ILRU has received funding from RSA since 1985 to conduct long-term training for management staff of independent living centers. These and other major ILRU projects have allowed for collection of extensive data on management concerns faced by independent living center boards of directors and staff.

Concerns Facing Independent Living Center Managers

From the beginning, managers of independent living centers have had to deal with a constellation of administrative and operational issues common to all complex organizations. These include issues around effective use of the board of directors, fund raising, personnel management, fiscal management, and program evaluation. In this regard, independent living centers are no different from other non-profit organizations or from many for-profit organizations that are trying to find ways to make their organizations function more effectively.

Since 1985, ILRU has carried out periodic surveys of the independent living field using a modified Delphi survey technique to identify management concerns and priorities. These surveys confirmed that, indeed, independent living centers are confronted with the full range of general management issues faced by other organizations.

The first of these surveys of center executive directors, conducted in 1985, revealed that the highest priority involved doing effective fund raising, followed by using governing boards effectively, conducting program evaluation and assuring quality, diversifying funding bases and contingency planning, providing for staff development, mounting community and public relations programs, doing long-range planning, reaching out to underserved populations, building working teams, and involving people with disabilities in all aspects of center operations, e.g., on the board and in staff and volunteer roles (Smith et al., 1991). Virtually all of these concerns, save the last, are ones that might be cited by the executive director of any organization, regardless of whether or not it is involved in independent living service delivery. The last issue cited, dealing with consumer involvement, gets to the essence of the independent living philosophy — people with disabilities have to be involved at virtually all levels, including management and service delivery, if services are going to be responsive to the needs of those for whom they are intended.

Between 1988 and 1990, ILRU conducted a series of Delphi surveys to identify issues and priorities related to management of specific services offered by centers. In 1988, survey activities focused on issues around management of peer counseling services. In order to get a sense of issues and priorities as perceived by both service delivery staff and center administrators, sur-

veys were sent to the managers of the peer counseling program, as well as to the executive directors of centers. The top three issues identified by executive directors with regard to management of peer counseling services were evaluating peer counseling services, documenting service delivery and service outcomes, and reducing risk of center liability. The top three issues cited by managers of peer counseling programs were setting peer counseling program goals and objectives, recruiting persons with various disabilities and areas of interest to serve as peer counselors, and documenting services with minimal paperwork (Smith et al., 1991).

In 1989, executive directors and managers of independent living skills training programs were surveyed using the same procedure. The top three issues around management of independent living skills training programs identified by center executive directors were securing and maintaining adequate funding to support independent living skills training programs, dealing with a lack of community resources (e.g., accessible housing, personal assistance services, transportation), and incorporating self-advocacy skills into all aspects of the skills training program. The top three issues identified by independent living skills program managers were overcoming lack of consumer motivation and self direction, assuring that independent living planning is consumer directed, and developing individualized plans that address needs identified by consumers.

In 1990, survey efforts focused on management of community or systems advocacy programs. Again, center executive directors were surveyed as were managers of systems advocacy programs. The top three issues identified by executive directors with regard to systems advocacy efforts were dealing with consumer apathy and assuring that center board and staff members were not expected to carry the whole advocacy load, balancing advocacy and service delivery activities, and obtaining funding that is not earmarked for non-advocacy services, such as peer counseling or information and referral. The top three issues identified by advocacy program managers were teaching consumers how to use advocacy skills effectively, finding adequate time for center personnel to devote to advocacy, and networking effectively to build local, state, and national coalitions to work on advocacy issues. A more thorough discussion of the top ten issues identified by executive directors and program managers surveyed over all three years can be found in *Rehabilitation Education*, volume 5, pages 101–111, 1991.

In the last quarter of 1992, 20 executive directors representing centers from rural and urban areas, different parts of the country, varying sizes in terms of staff and budget, and including more established and newer centers were again surveyed concerning their perceptions of the most pressing management issues related to operating centers. The results, not previously published, were somewhat of a surprise to ILRU staff involved in the survey. Given the recent passage of ADA — with its mandate around services designed to foster civil rights of people with disabilities — and the impending signing of the 1992 Amendments to the Rehabilitation Act — with significant changes in the manner in which centers were to be funded and in oversight responsibilities for center operations — there was an expectation that management issues related to ADA services and to implementation of the Rehabilitation Act Amendments would likely be identified as high priorities by executive directors.

The results of the 1992 survey are summarized below according to the major center management issues identified as most important by executive directors.

1. Advocacy — Funding; building coalitions; achieving proper balance with services; handling risks; involving staff; receiving credit.

2. Operationalizing IL Philosophy — Having staff who understand and put philosophy into practice; increasing "cross disability-ness" of the center.

3. Fundraising/Development — Advantages and disadvantages/demands and rewards of various fundraising strategies; sustaining funding levels; involving board in fundraising.

4. Personnel — Having people on staff who practice independent living philosophy in delivering services; having a cross-disability, cross-cultural staff; maintaining a satisfied, productive workforce, being aware of legal issues in personnel management.

5. Board of Directors — Recruiting board members appropriate for a complex organization; maintaining a strong board with leadership capabilities; dealing with the ineffective classical board model.

6. Center Operations — Coping with demand which exceeds capacity, impacting morale, burnout, shifting priorities, communication; managing budgets, cash flow, lines of credit, grant proposal development; having effective program evaluation.

7. Planning — Creating a strategic vision for the center; finding time for planning; moving from crisis management to controlled growth; managing growth and expansion.

8. Marketing — Promoting center services to consumers and promoting independent living issues to commu-

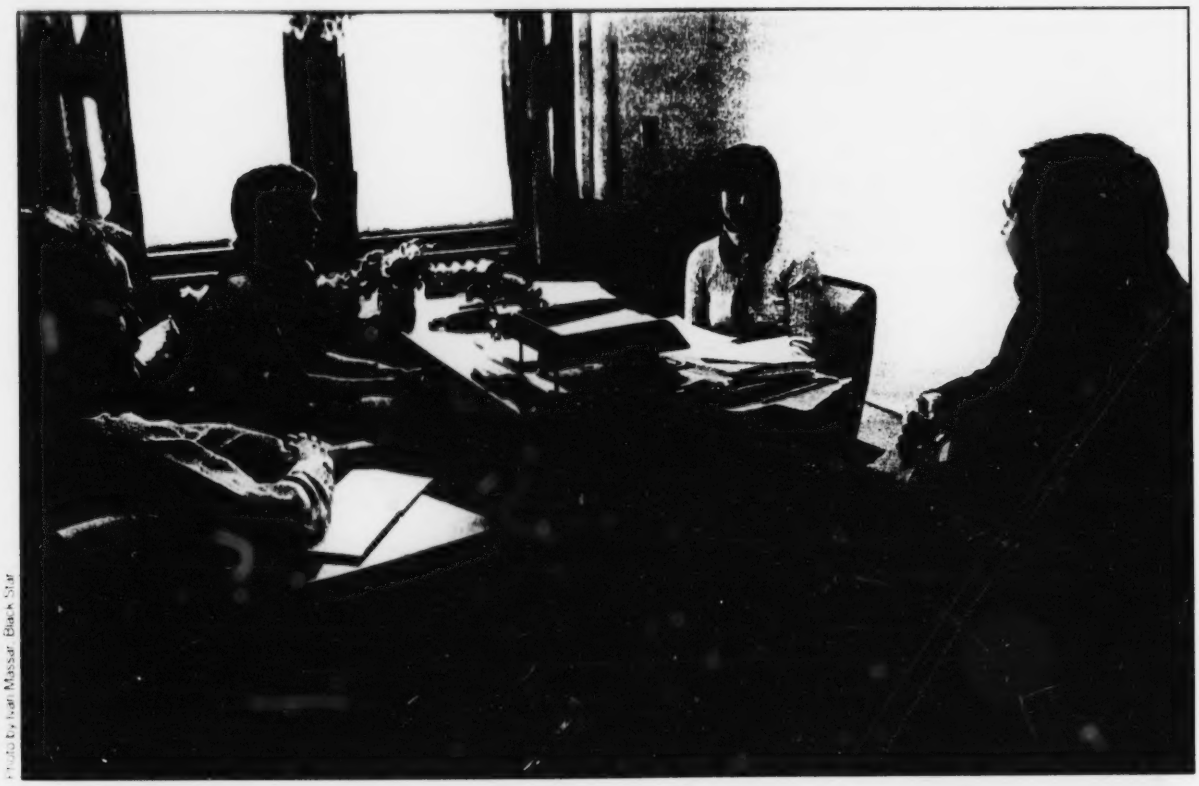

Photo by Joan Myssar, Black Star

nity leaders; making effective in-roads into the corporate community; marketing an ILC in rural areas.

9. Leadership Development — Internally and within "the movement," have we outgrown our leadership or simply left everyone else behind?

10. Networking — Connecting with the corporate community; educating and influencing how communities address disability issues by serving on community-wide committees and boards; establishing and maintaining successful and appropriate collaboration with other organizations.

11. Personal Life/Health Maintenance — Maintaining a personal life and good health while keeping up the work level and involvement necessary to be a successful center.

What was surprising about these results was that issues around ADA and the Rehabilitation Act Amendments of 1992 were not prominent among the top issues identified. However, many of the issues identified, including those dealing with cross disability involvement in center operations, sustaining funding levels, and having effective fiscal and personnel management procedures are covered in standards included in the 1992 Amendments. Also, management issues around ADA were identified by a few participating center directors, but did not garner enough votes in later rounds of the Delphi process to be listed among the highest priorities.

The striking finding of the survey, at least to ILRU staff who have been studying the field for over 16 years, relates to the similarity of these findings with findings from the 1985 survey of center directors. Issues relating to board effectiveness, fundraising and development, planning, and marketing of services continue to figure prominently as major concerns for center directors. The question this raises is, "Has progress been made over the past eight years in furthering the capabilities of centers to deliver independent living services — including systems advocacy — effectively?"

Implications of these Issues for Research and Training

In searching for the answer to this question, it is important to examine what sets independent living centers

apart from other organizations which serve people with disabilities. While data collected through surveys are important in identifying issues and setting priorities, such information cannot be used independently in assessing the importance of factors that influence development of a field. What is required, in addition to quantitative data collected through surveys and reports (such as the annual "A to K" reports that have been required of centers by RSA), is information that can only be gathered through in-depth discussion and analysis involving people who are engaged in operation of centers on a daily basis.

ILRU staff have been working closely with board and staff members of independent living centers on a variety of issues over the last several years. These efforts have involved studies of issues around delivery of independent living services in rural areas, model approaches for delivering peer counseling services, and ways of improving service systems through innovations in funding and community networking. Furthermore, training programs are conducted routinely in a manner that allows for in-depth exploration of management and service delivery issues critical to the field.

The value of frequent and substantive interaction with people immersed in independent living has been of crucial importance in identifying factors that continue to pose problems in development of an independent living service delivery system in which centers are the vehicles for effective implementation. These interactions have allowed for identification of a number of factors impinging on management of centers that offer special challenges in developing and conducting research and training projects (Smith et al., 1991). These include:

- the commitment of centers to hiring people with disabilities, many of whom, because of previous discriminatory practices in education and employment, have had few opportunities to develop management skills;
- the lack of standardized entry-level preparation of persons working in centers, who come from diverse backgrounds that may or may not include preparation in organizational management;
- variations in the scope and range of services offered from center to center in their efforts to be responsive to community needs and consumer preferences;
- limitations in staff sizes, making it extremely difficult to free time for staff development that is critical to organizational maturation;
- severe budget constraints, creating problems both with regard to release time to allow staff to participate in activities to enhance skills, and in paying for staff development options (e.g., college courses, continuing education, regional and national conferences) that may be available; and
- assuring accessibility to staff development opportunities through provision of accommodations (e.g., sign language interpreters, accessible transportation, provision of personal assistance) that, while absolutely essential, also increase staff development costs.

These issues create a set of problems for independent living centers that compound developmental difficulties that are experienced by all organizations. Information gathered by ILRU staff suggests that the problems faced by centers may be due, at least in part, to efforts to adopt management structures and procedures that do not work as well in centers as in other non-profit organizations. For example, independent living centers adopted a model for organizational governance that borrowed from the model used by most non-profit organizations. This "traditional" model requires a board of directors, either elected by a membership or selected by existing board members (the self-perpetuating board), which hires the executive director, who then serves at the pleasure of the board.

ILRU staff's frequent interactions with the field indicate that almost invariably, when centers have encountered serious problems — often resulting in termination of the executive director and sometimes resulting in closure of the center — it can be tracked back to problems with the working relationship between the governing board and the executive director. In exploring board issues with ILRU's training program participants, executive directors often indicate that they do not have adequate authority to deal with management issues, including personnel problems and fiscal problems, in a timely and expeditious manner, and that they often perceive the board as being inappropriately involved in operational issues, rather than in policy issues.

Although research on this issue is lacking, at least one possible solution that needs to be explored involves consideration of other board models. A number of more established centers, including the Ability Center of Greater Toledo, Access Living in Chicago, Paraquad in St. Louis, and Resources for Living Independently in Philadelphia, have adopted a board structure in which the executive director, who serves as the chief operating officer (COO) in most centers — serves as president and chief executive officer (CEO) of the center and is a voting member of the board. This model more closely resembles the for-profit corpo-

rate model than does the model used by most centers that was borrowed from the non-profit sector. Individuals from organizations which have adopted this "corporate" model indicate that it gives them greater authority to develop and implement plans that benefit the center, *and* that it improves communication and collaboration between the executive director and the governing board of the center.

In fact it should not be a surprise that the "corporate" model might work more effectively for centers than does the more traditional non-profit governing model. Centers for independent living are predicated on the notion of individual initiative and the opportunity for achievement. As compared with many other non-profit organizations, independent living centers do not rely on appeals for sympathy and charity as a means of generating funding for support. They have grown up around the notion of developing and offering high quality services that can be marketed to individuals with disabilities and public and private organizations serving individuals with disabilities — an entrepreneurial approach. Rather than conducting appeals for support based on helping the "needy," independent living centers have endeavored to develop services that can be marketed at a competitive price in the community. These include services for individual consumers, such as peer counseling and skills training, and services for organizations and businesses, such as accessibility surveys to assess compliance with ADA and other disability-related legislation. The entrepreneurial orientation of centers can be attributed, at least to some degree, to limited funds that were available from public sources to support independent living centers.

Some center management problems, such as the questionable fit of the non-profit board model with independent living centers, can be traced back to the original intent of Title VII funding for centers. To quote from a report of Institute on Rehabilitation Issues, published by the Arkansas Research and Training Center in Vocational Rehabilitation (1990, p. 43), "Many saw Part A primarily as a means for providing ongoing funding for ILCs. . . . Many similarly saw Part B merely as 'start-up' or 'seed' money and not as a source of ongoing core funding for ILCs." However, in implementation, Title VII Part A funds, intended for the purchase of services from centers by state vocational rehabilitation agencies and other service organizations, were not allocated at all with original passage of Title VII, and have amounted to no more than a few million dollars per year since they were first allocated in 1986. Title VII, Part B funds have been increased at a modest rate since 1978, and continue to provide core funding for center operations.

The expectation that centers would generate support through fee-for-services and other fund raising activities was implied in the original legislation. Documentation of fund raising efforts was also included in the "A-K" standards used by RSA in recent years to evaluate the performance of centers. The 1992 Amendments to the Rehabilitation Act is the last of seven standards for resource development activities. The latest draft of this standard states, "The center shall conduct resource development activities to obtain funding from sources other than this chapter" (RSA, 1993). How this standard will be translated into indicators used in assessment of center performance will not be known until the indicators are released in late 1993.

In essence, Title VII created an organizational hybrid with some characteristics of traditional non-profit service organizations operating with public support, such Area Agencies on Aging; and some characteristics of for-profit and certain non-profit organizations, such as hospitals, to develop and market services to individuals and third-party payors. Since they were first established, independent living centers have been struggling to find the management structure that best suits their missions, goals, and objectives in promoting optimal independence for people with all types of disabilities. Progress is being realized, and strong and stable independent living centers are being established throughout the country.

Implications for Management Research and Training

The independent living movement has experienced growing pains similar to those experienced by other social movements that have found expression in legislative initiatives and service programs (e.g., minority business set-aside programs resulting from the civil rights movement). The rapid growth in the number of independent living centers has been accompanied by a few false-starts and setbacks. Centers have struggled to come to grips with the difficult requirements of responding to administrative demands of social service agencies while trying to address requirements of funding diversification typically required of more entrepreneurial organizations in the for-profit sector.

Additional research is required to identify administrative structures, including board-staff arrangements, that best suit the needs of independent living centers. Furthermore, research on successful strategies for funding diversification needs to be stepped up. A high priority in this regard relates to research on regulatory and administrative requirements (e.g., the efficacy of

payment contingent on delivery of services by persons with specific professional credentials), that may place centers at a severe disadvantage in marketing their services effectively.

As important as the need for research on management issues for independent living centers is the need for commitment of more resources to training, technical assistance, and other mechanisms for disseminating information to the field successfully. Problems related to the absence of standardized entry-level training for center staff have forced centers to divert resources, most notably staff time, to training and orientation programs that might have been committed to direct services had other training and orientation resources been available.

More attention needs to be focused on entry-level preparation for people interested in careers in independent living. However, such training opportunities need to be developed with an eye to accessibility and accommodation of persons with disabilities. Simply offering an educational program on independent living using the traditional college or university approach is not likely to produce the desired result of expanding opportunities for people with disabilities. In addition to the costs that most students assume in pursuing educational opportunities, students with disabilities are often forced to commit substantial funding to re-establish support services required to live independently. Such support services may include routine personal assistance, accessible transportation, or access to brailling capabilities. For many people with disabilities, the costs of re-creating support services that they have developed in their current living environments make pursuit of educational options infeasible.

The recognition of limitations in existing educational opportunities for people with disabilities argues strongly for redoubling efforts to capitalize on technology effectively to create learning opportunities that are cost effective and accessible. The technology exists to bring an array of educational options into the homes, worksites, and other sites where people with disabilities can access them effectively to enhance knowledge and improve skills. If there is a priority for training in independent living, it is to explore more effective use of technology in creating educational options that truly provide opportunities for people with disabilities that are comparable to opportunities available to other people.

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Independent Living: *Driven by Principles of Democracy*

To hear some traditional rehabilitation providers talk, you would think independent living centers are a subversive group that threatens the basic system of democracy in our country. Yet, if you understand the history of independent living and track its impact on the lives of hundreds of thousands of Americans with disabilities, you will see that independent living centers are born from the very premise of democracy.

Independent living centers represent government at its best, and that is government "of the people, by the people, and for the people." Independent living is made up of people with disabilities operating and controlling services provided to others with disabilities in their community. Many of the individuals involved in the operation of independent living centers have at one time needed, or still need, independent living services. Having people with disabilities involved in independent living centers brings unique insights into how best to meet the needs of other individuals with disabilities.

When Congress inserted independent living into the Rehabilitation Act of 1973, with the 1978 Amendments, it was viewed by many rehabilitation service providers as an experiment to measure the difference in service delivery by involving the constituents of such services in the operation and control of programs that affected them. The experiment has proven both interesting and exciting. For Americans with disabilities who have benefitted from the advocacy and services available through independent living centers, it has meant living a richer and more fulfilling life based on each individual's values.

Photo courtesy Access Alaska

Duane French

Director
Access Alaska, Inc.

Outcomes: More Than Jargon!

It is unfortunate but the term "outcome" has become bureaucratised to such a degree that it is fast becoming meaningless. "Outcomes" in their truest form are about the differences in an individual's life resulting from advocacy and/or service provision by independent living centers. "Outcomes" as measured by the bureaucracy focuses so much on process that it misses the real substance of what constitutes truly successful "outcomes."

I remember the first person with a disability assigned to work under me as an independent living specialist in Nebraska. He was a 37-year-old who worked in an autobody shop until he fractured his lumbar vertebrae in a motorcycle accident. He lived in Colorado at the time of the collision and was hospitalized in Denver for six months. He then returned to his hometown in Nebraska (population of about 2,500) to live with his parents.

In my first meeting with the young man I was surprised to see that he spent nearly all of his time in bed and his mother served as his personal assistant. Whenever he did get out of bed, he used a heavy recliner wheelchair and was totally dependent. After I worked with him for six months, he bought a new lightweight wheelchair, was driving a car with hand controls, was his own personal assistant, opened his own bodyshop and started working on cars again. He developed new friendships and renewed old ones making his social life very active. With each success in his life, he felt more comfortable taking new risks and developed an intimate relationship with a woman who became a significant part of his life.

This young man did the necessary work to make these significant strides, which he accomplished with information, individual advocacy (until he learned to advocate on his own behalf), referral to other agencies, skills training, service coordination, and support made available to him through an independent living center. His decision-making process was directed and controlled by him based on what he believed to be important. The empowerment gained through directing his own independent living services gave him a sense of control and promoted his desire to take other risks and to expand his skills to live more independently.

The story of this young man speaks to the real meaning of "outcome."

Encouraging Creativity Within The System

Another expectation Congress has for independent living is to bring a new creativity into the realm of advocacy and service delivery. To comply with the expectations and demands made by funding sources, independent living centers have been forced to develop a system of documentation all too similar to that used by traditional rehabilitation programs. In my role as executive director of Access Alaska, I spoke about the system of documentation with a new staff member who is an Alaskan Native with a severe disability. His complaint about our need for written documentation was that Native Alaskans document things, including their history, through stories told from generation to generation. Although he went on to adjust to our system, it may be that our system could benefit from the wisdom of his culture.

The more I thought about this staff member's comments, I wondered why we have allowed independent living to conform to a method of documentation that is so cumbersome and doesn't tell the real stories we need to communicate. Every time I go to a bookstore and see the fast growth in books on tape, it makes me aware that we could easily document via audiotapes rather than on paper. An audio recording would add a richness to documentation that currently doesn't exist. While this is a rather benign instance, it made me realize that those of us in independent living have gotten overly cautious to avoid problems with funding sources.

Independence According To Cultural Values

Access Alaska is fortunate to have staff who are Alaskan Natives and who have taught us much about developing independent living services in Native Alaskan Villages that are born from the values of each Village and Tribal Council. We discovered that decisions are not customarily made by individuals, but are discussed and decided upon by a Village Council. This approach caused us to change our approach to independent living to be more flexible in how we apply it within the various diverse cultural perspectives in this state.

Another critical understanding gained from Alaskan Natives is that programs and services available in urban communities, reflective of the majority culture, are neither effective nor welcomed in Native Alaskan villages. In the first meeting with a Native leader at the Tanna Chiefs Conference in Fairbanks, he said "You think we are really happy that you might start a program in our Villages, but we are not! You know how to make a program work in white man's culture but not in ours." The Interior Alaska Independent Living Services program would never have been responsive to the needs of Alaskan Natives in rural villages without the commitment to hire a Native Alaskan with a significant disability from an Interior village.

Once the disabled Native Alaskan, who had been a consumer of Access Alaska, was hired and trained as an independent living specialist, he and representatives from the Tanna Chiefs Conference shaped and formed the services available through the program. The Interior Alaska Independent Living Services program has proven successful and has made it possible for Access Alaska to gain credibility among Native Alaskans. Access Alaska has learned too that trust must be earned with each Native Corporation and Village Council to be credible in addressing the needs of Native Alaskans with disabilities.

Independent Living Can Happen Wherever People Live

In many native villages in rural and remote areas of Alaska, one wonders how a person with a disability could live there and function independently. Of course, people from outside of Alaska question how a person with a disability can live in Alaska at all! What Access Alaska has learned is that independent living can happen wherever people live. This isn't to say that there aren't major challenges for Alaskans with disabilities in rural and remote parts of the state. Everyone who lives in a rural and remote part of Alaska is faced with similar challenges.

I have been in Fairbanks when it was 57 degrees below zero and I thought my lungs were going to freeze. But everyone else was just as cold! The climatic extremes in Alaska do shape the kinds of services offered. Cutting wood, carrying water, and snow removal are just a few of the Personal Assistance Services required in Alaska. The problems most negatively impacting on Alaskans with disabilities have less to do with weather than with the state's archaic vocational rehabilitation program and other outmoded services. Unfortunately, Alaska is much like many other states in this regard.

Experiencing The Wonder Of Freedom

To live in Alaska — one of the most beautiful places in the world — allows Alaskans with disabilities to reap the many benefits of being surrounded by the beauty of Alaska's natural environment. We are awed by the mountains, moved by the streams, rivers, inlets, and ocean, and entranced by the wildlife. Independent living in Alaska and throughout America has finally made available to Americans with disabilities the freedom to live as full and rich a life as we choose. Independent living has proven that government, when it joins forces with the people it serves, can be successful in moving all of our people toward "the pursuit of life, liberty, and justice for all."

How Parent Networks Are Working with Independent Living Centers

Martha Ziegler

Director
Technical Assistance
for Parents Programs

Kathryn Erickson, parent and executive director of Pathfinder, which operates the Parent Training and Information (PTI) program in North Dakota, recently said:

> People from the independent living centers are teaching us what they needed and didn't get when they were in school.

Collaboration between parents in the PTI projects and adults with disabilities in the independent living centers and through other avenues is producing a synergy that enhances the work of both groups and has strengthened the disability advocacy movement. The most recent and most dramatic result of this collaboration is the Americans with Disabilities Act (ADA). Parents, including nearly all of those associated with PTI programs, advocated alongside their friends with disabilities for enactment of that law and, since enactment, they have continued to work together in training workshops, public forums, and in the production of information materials.

Judith Raskin, executive director of New Hampshire PIC and director of the national Peer and Family Training Network Project on the ADA, reports that that project

> ***Aloha!*** *I'm Anne Smith. I have been in Hawaii for seven months. I am a wheelchair user. I just spent four months having my house renovated so that I can reach everything. My home and living in Hawaii are a life-long dream come true.*
>
> *I graduated from San Jose State College with a major in sociology and a minor in psychology. After four years as a social worker I went back to school and obtained my master's degree in education. I taught special education on the Island of Guam for 16 years.*
>
> *As an Information Specialist with LDAH [Learning Disabilities Association of Hawaii, which operates the Parent Training and Information project in Hawaii] I feel I have come full circle as a life-long advocate of learning. I used to work with children and now I work with parents, helping them with educational plans and placement. I see myself as a life-long learner.*

. . . utilizes a peer training model. The training is provided by a team of individuals: one parent/family member and one individual with a disability. In addition to modeling, the project encourages the PTIs who are hosting the training to work with their local independent living centers (ILCs) to publicize the training and encourage adults with disabilities to attend.

Nearly all the centers that operate PTI projects work closely with ILCs and other groups of adults with disabilities in permanent or ad hoc coalitions to conduct advocacy activities within their states. It should be noted that while a PTI and an ILC, as federally funded programs, cannot lobby, the incorporated umbrella organizations that implement these programs can conduct

such activities using other funds and keeping careful records.

The leader in parent/consumer collaboration in advocacy is Chicago's 25-year-old Family Resource Center on Disabilities (FRCD), originally known as the Coordinating Council for Handicapped Children. Executive Director Charlotte Des Jardins has devoted most of her adult life to advocacy on behalf of people with disabilities and their families. Des Jardins has described some of this early history as follows:

> . . . in the spring of 1969, I met Rami Rabby, founder and head of the National Federation of the Blind of Illinois. We immediately began working together, participating in activities to prod the Chicago Board of Education to accelerate the implementation of our new state mandate. We made presentations at many public hearings and public forums, where I met other disabled activists. One of these was Augie Christmann, Chairman of the Congress of Organizations of Physically Handicapped (COPH), who was another powerful influence in the Illinois civil rights movement for people with disabilities. Others were Rose Wilson, editor of COPH Bulletin, and Dennis Schreiber, founder of Advocates for the Handicapped (in 1973)—but now better known as founder and head of DARE (Disabled Americans Rally for Equality).
>
> Our collaboration intensified in 1976, when Augie Christmann, Margaret Pfrommer (also from COPH), Rami Rabby and I were on the steering committee of the Illinois White House Conference on Handicapped Individuals.
>
> It was after the National White House Conference, in 1977, that

Photo courtesy Chicago Tribune

Access Living was established as the first independent living center in Illinois.

Access Living opened new opportunities for collaboration in systemic advocacy activities. Marca Bristo, President [newly selected Chairperson of the National Council on Disability], and Jim Charlton, program director, soon became influential policy makers, not only at the state level, but at the national level as well. FRCD joined Access Living, ADAPT, DARE, COPH, and other consumer organizations in prodding the Chicago Transit Authority into providing accessible public transit.

FRCD worked with the adult disability groups in Chicago on a series of state and national efforts throughout the 1980s. Des Jardins goes on to say:

> The movement that made the strongest impact on collaboration between FRCD and consumer organizations was the civil rights movement which swelled with the introduction of the Americans with Disabilities Act (ADA) legislation. The ADA captured the imagination of parents, as well as people with disabilities, who recognized this unprecedented legislation as the most comprehensive civil rights legislation for persons with disabilities. The ADA motivated parents to collaborate with people with disabilities more than ever — and to recognize the natural bonds which make parents, family members, and people with disabilities natural allies as they worked together for its passage.

A review of the parent centers indicates that there is a strong desire to work even more closely with the independent living centers and in general with adults with disabilities, but there is an accompanying frustration with the lack of funds that are needed to strengthen these ties. The recent awarding of Rehabilitation Services Administration (RSA) grants to five parent centers that operate PTI projects will help. Cheron Mayhall, executive director of COPE (Coalition in Oregon for Parent Education), one of the winners of the RSA competition, says:

> The infusion of these new resources will make an enormous difference for transitioning youth and young adults and their families. Project CHOICES provides for strong working alliances with several programs administered through the University of Oregon, with the State Transition Systems Change Project which is administered jointly by the Department of Education and Vocational Rehabilitation, with Centers for Independent Living, with Oregon's Youth Transition Program, and a number of other efforts on behalf of young adults exiting schools

with hopes of achieving adult lives that are satisfying and affirming.

Several parent centers submitted proposals jointly with independent living centers in response to the RSA competition. Unfortunately, limited funds allowed only five of the 68 PTIs to receive grants.

Experience has demonstrated to many parent centers the very positive effects of modeling by successful adults with disabilities. Barbara Buswell, co-director of PEAK in Colorado, has summed up the importance of this modeling, both for the internal operation of the parent center and for impact on the general public:

> Since November, 1992, an individual with a disability has worked at PEAK in our sales department. In addition, he has become a part of our curriculum review process, is writing articles for our PTI newsletter, and is making presentations at PTI training workshops.
>
> Adults with disabilites have played critical roles in PEAK's training efforts. In the yearly Inclusion Conference which PEAK cosponsors with three other groups, an individual with a disability has always served as a keynoter and individuals with disabilities also lead concurrent sessions. This leadership by individuals who themselves have experienced disability has been critical in moving the individuals particpating in this conference forward on implementing practices that include students with disabilities fully.

One of the most exciting developments has been the inclusion of people with cognitive disabilities in the work of the parent centers. PEAK's Inclusion Conference always includes people with mental retardation in its program, for example. Furthermore, several PTI projects report that they employ people with mental retardation through supported employment. Sharon Bishop, director of PRO-Oklahoma, reports that PRO-Oklahoma served on the committee for the First People's Choice conference in Oklahoma, and she added, "We continue to network and collaborate with People First groups statewide."

PTI projects have a variety of formal relationships with ILCs and other organizations of adults with disabilities. Two PTIs are operated by organizations that began as adult groups: the Nevada PTI is operated by Desertview, which provides supported living services for people with disabilities, and one of the California PTIs is operated by the Disability Rights and Education Defense Fund (DREDF), an organization founded by adults with disabilities. In Alabama, the PTI director serves on the Board of Directors of the ILC. Several parent centers have ILC representatives on their boards, and all have adults with disabilities on their boards, as now required by law.

Several PTIs employ adults with disabilities on their staffs. The New Hampshire PTI reports that 48 percent of its staff are people with disabilities. Colorado, Massachusetts, and Tennesee all have staff who are part of a supported employment arrangement. Tennesee and Massachusetts also have PTI staff who serve on the Board of Directors for supported employment programs. West Virginia has assistance from several volunteers with disabilities.

LeAnne Nelson Dahl was first a member of the Board of Directors at PACER, the PTI in Minnesota, and then she joined the staff, where she served for 13 years participating in many projects, including the parent training program. She submitted the following comments about her involvement at the PTI:

> As an adult with a disability, I feel that it should be imperative that PTIs hire individuals with disabilities. While conveying credibility, it also provides emotional support to the parents, children, and young adults that the Center serves.
>
> I worked for PACER . . . for over 13 years. During that time I spoke to parents and professionals about what it's like to grow up with a disability. In the process I hoped to impress upon them how important it is to help their son or daughter realize their own potential. I urged the audience to start nurturing a healthy self esteem in their child as soon as possible. I spoke to them about allowing children and young adults to have choices, express their own opinions, and to treat them as individuals — in essence, giving themselves permission to let go and let the person with a disability become their own person. It always amazed me to see parents beginning to think of their own children's possibilities of actually becoming adults with lives of their own.
>
> I also had the opportunity to work in the COUNT ME IN Puppet Program where I spoke to children with and without disabilities. It was a joy to watch attitudes change in children without disabilities as they discovered that there really isn't any difference in feelings, although we may do some things differently. Children with disabilities also need good role models.
>
> I appreciate being asked to write articles for the PACESETTER because it gives me the chance to further develop my skills in the writing field as well as another vehicle to share my thoughts and ideas with

families about living with a person with a disability. Little did I know at that time, but this writing proved to be a turning point for me. I decided to leave PACER to devote more time to writing and have more quality time with my husband, family, and friends.

Chicago's Family Resource Center on Disabilities also has considerable experience with staff members who have disabilities. Des Jardins reports:

> While working with people with disabilities to effect systemic changes, FRCD confirmed the value of people with disabilities as employees by hiring them in four federally funded projects: BUILDING Project I, an advocacy project for learning disabled youth; the SHARE Project, a disability awareness project; BUILDING Project II, a family networking transition project for high school youth with disabilities and their families; and the MAINROADS Project, a self-determination project for high school youth with disabilities.
>
> The MAINROADS Project, which teams parents and adults with disabilities as mentors to promote self-determination and independent living in youth with disabilities, is a natural culmination of the FRCD philosophy of collaboration with people with disabilities.

Most of the PTIs include adults with disabilities in some part of their training for parents. The Wisconsin PTI conducts joint training with the ILC. Often the PTIs and ILCs exchange presenters and speakers. Currently, Colorado, Kansas, and Hawaii are participating in the Partnerships for Policy training that is sponsored by several Developmental Disabilities state planning councils. These are a series of weekend workshops designed to train adults with disabilities and parents to become more effective advocates within their states. As director of the Massachusetts PTI, I also have participated in this training in Connecticut and Texas. Often, the PTIs and ILCs co-sponsor and co-present; one example is Missouri's disability awareness workshops.

Occasionally parent centers have actually been instrumental in starting, or helping to start, new independent living centers. Parent centers in Texas and Tennessee have recently provided in-depth technical assistance to groups hoping to establish an ILC. Both parent centers are prepared to continue to help after the fledgling ILCs get funded and into operation.

Practically all the PTIs make referrals to the ILCs and the ILCs to the PTIs. PLUK, the PTI in Montana, collaborates with four ILCs in the use of Technology Act monies used to disseminate information about assistive technology. The ILCs specialize in daily living applications of assistive technology, while PLUK specializes in more "high tech" applications. Kathy Kelker, executive director of PLUK, reports that "about 30 percent of the individuals served by PLUK are adults with disabilities and this number is growing. More and more our organization is being seen as one which is responsive to the consumer."

Following are some additional examples of collaboration between PTIs and ILCs:

- Colorado, Massachusetts, and Minnesota involve adults with disabilities in focus groups to help plan activities and projects.
- Alabama works with parents with disabilities who also have children with special needs.
- Missouri exchanges calendar information with the ILC.
- The Tennesee PTI shares a staff person with an ILC.
- Adults with disabilities in South Carolina make extensive use of that PTI's resource library.
- The Delaware PTI director is involved with a project that would allow adults with disabilities to own their own homes.
- Several PTIs report collaboration around newsletters and other publications; booths and exhibits; consultation around accessibility of prospective meeting sites; and consultation between staffs around such subjects as the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, the ADA, and state laws and regulations.

Patty Gerdel, director of Families Together in Kansas, captured the views of the PTIs in the following comments about working with the independent living center in Kansas:

> Through the Pioneers project we have learned that there are wonderful national leaders in the ILC arena that we had never heard of. As we looked for speakers at Pioneers conferences, our PTI staff recommended leaders from the PTI arena. Again, we found that the ILC had not heard of the speakers we recommended. We learned that both PTI and ILC leaders are needed to get the full benefit of national and state leadership.
>
> Families Together, Inc. has worked closely with the Topeka Independent Living Resource Center for several years. As a result of this working relationship, we have discovered that our philosophies, and often our frustrations, are about the same.

Independent Living and Personal Assistance Services: *The Research, Training, and Technical Assistance Programs at the World Institute on Disability*

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In 1983, Ed Roberts, Judith E. Heumann, and Joan Leon left top posts in the California Department of Rehabilitation to found the World Institute on Disability (WID). They envisioned an organization primarily staffed and run by persons with disabilities, which would conduct research, policy analysis, model-program development, technical assistance, and public education on issues affecting the lives of people with disabilities.

WID is based on the principle of independent living, which Adolph Ratzka, a Swedish economist, describes as:

> *The right of all persons, regardless of age, type or extent of disability, to: live in the community, as opposed to living in an institution; have the same range of choices as everyone else in housing, transportation, education, and employment; participate in the social, economic, and political life of their communities; have a family; live as responsible, respected members of their communities, with all the duties and privileges that entails; and unfold their potential.*

Judy Heumann frames independent living in terms of basic autonomy: "Independent living is not doing things by yourself, it is being in control of how things are done." One of the primary issues in independent living for persons with disabilities is access to adequate, affordable, and autonomous personal assistance services (PAS). Indeed, the type and amount of publicly funded personal assistance services available can dictate where and how people with significant levels of disability live their lives. PAS is a priority issue at WID. This article will present a brief overview of WID's research and technical assistance in the area of personal assistance services.

Personal Assistance Services Research at WID

In 1983, WID received its first research grant from the Charles Stewart

What is PAS?

The World Institute on Disability defines PAS as assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society as a whole. These include: personal maintenance and hygiene, mobility assistance, household maintenance, infant and child care, life skills support services, security-enhancing services, work related support services, communication services, service coordination, and management. PAS is an array of services necessary for persons of all ages and with all types of disabilities (including physical, cognitive, communicative, and psychiatric) to live independently.

Mott Foundation to study the availability of state funded PAS. Simi Litvak was hired to conduct the first national study of PAS. Dr. Litvak recalls, "WID staff expected to find a couple of dozen programs. They assumed that the only PAS programs were state-run independent living programs. After reviewing the literature (which consisted primarily of government publications, program brochures, state and federal legislation, and program regulations), I discovered there were a variety of sources of PAS." She then called Medicaid departments, Social Services departments, and independent living programs (ILPs) in each state. She described the nature of the services, and then asked if their departments or any other state departments had programs that offered PAS. By the time the project was completed, over a year later, 157 programs in 49 states had been identified and surveyed. The findings were reported in a groundbreaking study, *Attending to America: Personal Assistance and Independent Living* (Litvak, Heumann, and Zukas, 1987).

Attending to America described a patchwork of programs that vary dramatically in type, scope, and magnitude of services offered. Many programs provided a small amount of low-tech support services, such as bi-weekly homemaker services or periodic chore services to a less disabled and often elderly population. Other programs provided short-term intensive nursing and rehabilitative services (intended primarily for post-hospital treatment). Relatively few programs offered adequate levels of the wide range of daily services that many people with significant disabilities require. These PAS programs limit access through a variety of eligibility criteria (i.e. age, income, assets, disability type, type of residence and family) and restrict services by imposing various limits (Kennedy, 1993a). Some programs use highly supervised skilled professionals to provide relatively limited services, while a few offer extensive services performed by unskilled or semi-skilled providers, often trained by the consumers themselves.

This national survey established WID's legitimacy as an authority in the emerging field of PAS research, and other research grants soon followed. In 1987, the National Institute of Disability and Rehabilitation Research (NIDRR) at the Office of Special Education and Rehabilitative Services (OSERS) funded a series of in-depth interviews with selected PAS programs and a new national survey of all PAS programs. These studies examined the impact of federal funding source on key program features such as access restrictions, service limits, workforce issues, and fiscal constraints. In general, funding source was found to impact the design of PAS programs less than the political and historical circumstances unique to each state (Litvak et. al., 1990). A comparison between the 1984 and 1988 surveys suggests that average caseloads in existing PAS programs grew by over 10 percent, while costs grew at an even higher rate (Litvak and Kennedy, 1991).

Who Needs PAS?

Approximately 9.6 million people need the assistance of another person with basic personal maintenance, hygiene, and household tasks. This includes 7.8 million non-institutionalized people: 1.5 million people in nursing homes and 300,000 people in facilities for people with mental retardation (Bureau of the Census, 1990; Pepper Commission, 1991; LaPlante, 1989; Kraus & Stoddard, 1989). Two million people (26 percent of all non-institutionalized users) received some or all of their PAS from government sources. Most people receive PAS only through informal supports: family, friends, and volunteers (Bureau of Economic Research & WID, 1990). These figures do not include reader services for persons with visual disabilities or communication services for persons with auditory disabilities.

In 1988, the Office of the Assistant Secretary of Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services (HHS) awarded WID a sole-source contract to study programs utilizing the Medicaid Personal Care Option — the largest source of federal funding for PAS. Analyses of the 1984 and 1988 national survey data and a series of six site visits led to a report entitled *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit* (Litvak and Kennedy, 1991). This study found that, despite relatively strict federal requirements, states had developed very different Medicaid programs. For example, the Massachusetts Independent Living Personal Care Program allows consumers to hire and pay their own attendants and contracts with local independent living centers for administrative support and consumer training, while the Montana Personal Care Services Program contracts with a statewide private homecare agency that hires and trains attendants. More and more states, as they experience continuing revenue shortfalls, are looking to the federal matching funds available through the Personal Care Option to pay for their PAS programs.

WID's PAS research agenda has expanded beyond program analysis. WID and the Bureau of Economic Research at Rutgers University, under a joint grant from NIDRR, summarized the need for PAS in the U.S. population (WID & BER, 1990). In 1992, the Administration for Children and Families at HHS awarded WID a grant to study innovative models of PAS delivery in Sweden, Finland, Germany, and Denmark.

In 1990, WID, in collaboration with the Western Consortium for Public Health and InfoUse, became the first independent policy institute to be designated as a NIDRR Research and Training Center (RTC). Being designated as the Research and Training Center on Public Policy in Independent Living (RTC-PPIL) has allowed WID to continue its PAS research agenda and expand to other areas. Recent publications of the RTC-PPIL have addressed the availability of 24-hour PAS (Kennedy, 1993b), financing options for a national PAS benefit (Litvak, 1992), and liability issues (Sabatino & Litvak, 1992). The RTC-PPIL has also published a compilation of personal perspectives of PAS users from different disability groups (Weissman, Kennedy & Litvak, eds., 1992), and a resource manual, *Personal Assistance Services: A Guide to Policy and Action*. Current PAS research efforts at WID focus on identifying the cost implications of PAS program design to better inform current discussions of long-term care reform.

Training and Technical Assistance in Personal Assistance Services at WID

While the RTC-PPIL allowed an expansion of WID's training and technical assistance capacity with regard to PAS, the organization has been involved in such activities since its inception. Staff speak frequently on PAS policy (Ed Roberts, WID's President, introduces his attendant before each speech, explaining, "without him, I literally would not be here tonight"). Two symposia sponsored by the World Rehabilitation Fund in 1985 and 1987, opened a dialogue on PAS policy between WID and leaders of the international disability movement. Also in 1985, Dr. Litvak first presented her research findings at an invitational conference of researchers, government representatives, program administrators, consumers, and advocates convened by the National Council on Disability (NCD, then called the National Council on the Handicapped).

In 1987, NCD contracted with WID to develop legislative language on PAS. A task force was established that

WID and Participatory Action Research

Although WID staff has only recently labeled it as such, their PAS research is an example of what William Whyte (1991) calls "participatory action research" or PAR. In PAR, the researcher combines participant observation, explicitly recognized action objectives, and a commitment to carry out the project with the active participation in the research process by some members of the organization or group to be studied. At WID, PAR means involving persons with disabilities at every stage of the research process: determining the research topics, selecting samples, developing research instruments, collecting and analyzing data, and writing and disseminating the results. Dr. Litvak explains how this interaction affects her research:

If I had developed my research questions only from reviewing the literature, I might have emphasized caregivers, safety, institutional vs. community service costs, and liability. However, from my interactions with WID staff and persons working in Independent Living Centers (ILCs), I discovered that disabled people were overwhelmingly concerned with the capacity of the service system to enable them to lead productive, self-determined lives. This concern translated into research questions regarding the control of the provision of PAS, choice of provider types, worker wages and benefits, and restrictions on what, how much, when, where, and by whom certain PAS services could be provided.

included representatives of major national disability organizations, as well as government officials and disability experts. A series of meetings, centered around WID's research findings, culminated in proposed legislation for a national attendant services program, the Personal Assistance for Independent Living Act (PAIL). The main objectives of the PAIL are: (1) a vision of PAS as a civil right for all who need it; (2) recipient choice and control; (3) absence of work disincentives; (4) an adequate supply of providers; (5) adequate financing; and (6) maintenance and enhancement of existing state programs. The PAIL is being used by the Consortium for Citizens with Disabilities (CCD), a Washington-based umbrella organization representing over 100 disability organizations, as the basis of a broad-based national legislative strategy for the expansion and reform of PAS.

Through collaborations with such organizations as the American Society on Aging, the Society for Disability Studies, the National Council on Independent Living, the Gerontological Society of America, the National Health Policy Forum, the National Governor's Association, the President's Committee on Employment of People with Disabilities, the Grey Panthers, and the Association for Persons with Severe Disabilities, WID's research and policy efforts have been disseminated to a growing number of researchers, policymakers, and disability advocates. WID has worked with a variety of state and federal agencies, providing training and technical assistance on PAS-related issues to administrators, providers, consumers, and family members. A recent symposium sponsored by the RTC-PPIL, "Empowerment Strategies for the Development of a National PAS System," brought together disability leaders from 42 states and 9 countries to discuss reform options for state and federal PAS systems. Participants drafted a resolution calling for the recognition of PAS as a basic civil and human right.

WID has also become directly involved in the policymaking process. Hale Zukas and Ed Roberts testify regularly at state and national legislative hearings. Hale Zukas and Jae Kennedy served on the California Long Term Care Task Force, which was charged with improving the efficiency of LTC service delivery and restructuring the In-Home Supportive Services program (IHSS) to meet federal Medicaid requirements. Simi Litvak recently served on the Long Term Care Working Group of President Clinton's Health Care Reform Task Force.

The Growing Importance of PAS Policy and WID's Role in Systems Reform

PAS policy issues continue to grow in importance. States are currently faced with pressure to develop and/or expand systems of community-based services. A number of factors have contributed to this increasing demand. Institutions have become an expensive way of providing long term services. The spiraling costs of health care have impacted on the nursing home industry, dramatically increasing staffing and administrative costs. According to the Pepper Commission (1990), Medicaid nursing home expenditures now top $43.5 billion — over 80 percent of total long-term care expenditures. Institutions also face growing resistance from disability advocates who view institutional placement as a form of costly and dehumanizing incarceration, and describe community based PAS as a basic human and civil right (Degener, 1992; Ratzka, 1992). At least on an individual basis, home and community-based personal assistance services offer a cost-effective alternative to institutions (Kotler, Wright, Jaskulski and Kreisberg, 1985).

As medical technology improves and the so-called "baby-boom" generation ages, growing numbers of people with disabilities are seeking long-term services (U.S. General Accounting Office,

1991). At the same time, informal service provision by family members, the dominant source of PAS in this country, is becoming less viable due to shifting family structures and increasing numbers of women entering the workforce (Etheredge, 1987). An affordable system of government-funded PAS that augments existing support systems and creates a workforce of non-medical attendants to provide PAS is becoming an economic necessity (Ball, 1989). An expanded federal role in the provision of PAS is one likely outcome of the Clinton administration's health and long-term care reform efforts. Policy makers will need to pay particularly close attention to the views of those with the greatest expertise in PAS systems, the consumers of PAS, and the administrators of existing programs.

WID's research, training, and policy efforts will continue to play an important role in PAS systems development. Future PAS research at WID will focus on developing models of service delivery for diverse populations, including people with multiple disabilities, learning disabilities, and psychiatric disabilities. More research is also needed to understand the PAS needs of different age and ethnic groups. Training efforts will focus on increasing awareness of PAS issues among professional groups (particularly educators and rehabilitation specialists) and on training of persons with disabilities to assume a greater role in local, state, and national PAS policy development. ♦

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